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## Autonomy, Suffering, and the Practice of Medicine: A Relational Approach

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Autonomy, Suffering, and the Practice of Medicine: A Relational Approach

by

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A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
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## DEDICATION

In her memoir, *Morally We Roll Along*, performer Gay Zenola MacLaren recounts a childhood meeting with Mark Twain where he offered her this bit of advice: “Keep away from people who try to belittle your ambitions. Small people always do that, but the really great make you feel that you, too, can become great.” It is with immeasurable gratitude that I dedicate this work to the great people in my life whose support, encouragement, indefatigable patience, and love has always made everything seem possible.

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## ABSTRACT

In this project, I argue that the conventional view of personal autonomy that is operational in contemporary American culture, bioethics and medical practice places undue emphasis on individualism and a limited range of personal qualities and attributes (such as self-sufficiency). Instead, I argue in favor of a relational approach to autonomy which recognizes that each person that exists has certain minimal connections or relations to others, and these connections/relations are identity-forming. Unfortunately, current medical practices have tended to overemphasize individuality and choice (consistent with the conventional view) while minimizing or excluding these relational aspects. As a result, informed consent and patient choice have taken the place of a more robust, relational sense of autonomy in these contexts. But this approach fails to appreciate the ways that illness, uncertainty, and suffering may threaten identity and make it more difficult to meaningfully exercise autonomy—especially when construed in such narrow terms. Through an exploration of the nature of suffering and its effects on the person, I argue that to effectively treat ailments and alleviate suffering, patients must be cared for in ways that respect and restore identity, which also promotes autonomy. This kind of respect derives in part from acknowledging and nurturing relationality, especially in medical decision-making contexts.

## INTRODUCTION

The first goal of this project is to demonstrate that the conventional view of personal autonomy that is operational in contemporary American culture, bioethics and medical practice is the product of a particular political, philosophical, and cultural history that has placed undue emphasis on individualism and a limited range of personal qualities and attributes (such as self-sufficiency, self-interest, rationality) as constitutive elements of the ideal (Chapters 1 and 2). The legacy of this history (which continues to shape current understanding and use of the concept across many areas of law, medicine, and human subjects research) is that personal autonomy is most often defined and measured in ways that (a) minimize or deny the importance of certain social values, conditions, and relationships, and (b) are not representative of the characteristics, values, and/or experiences of certain persons or groups. As a result, the way that the concept is translated into policy or practice can be exclusionary, marginalizing, or ineffective in its intended purpose (Chapter 3). This can have the further consequence of actually undermining (patient) autonomy, which is the very thing it intended to promote and protect.



The second goal of this project is to argue in favor of a relational approach to personal autonomy, which is offered as a corrective to the aforementioned concerns (Chapter 4). My understanding of the concept recognizes that being a person in relation to/with others is a constitutive part of identity. Each person that exists has certain minimal connections or relations to others, and these connections/relations are identity-forming. The degree, quality, and infinite variability (across time, culture, values, relationship dynamics, etc.) of one's connections to others are a part of what gives individuals their individuality, and this sense of identity or individuality is the basis of the "self" that is referenced by the very meaning of the term "autonomy." Hence, the self—and therefore also personal autonomy—can only be conceived of in relation to others. As such, I offer a generalized account of the defining features of personal autonomy as understood through the lens of this relational approach, drawing attention to the way the contours of the concept may shift depending on the context of use and operational mode that is in focus (Chapters 5 and 6). Having outlined the problems with the traditional conception of personal autonomy, and having explained some of the features and benefits of the relational approach in general, I then shift the discussion to some of the specific ways that personal autonomy has traditionally been interpreted and applied in bioethics and medical practice.

The third goal of this project is to show how contemporary healthcare and clinical research policies and practices are built around a traditional conception of

autonomy which overemphasizes individuality and choice to the exclusion of relationality. I show that in bioethics and medical practice, it is common to substitute a robust notion of “autonomy” in favor of the more practicable idea of “autonomous choice,” which is often further reduced to “informed consent.” Rituals of informed consent are then utilized both as a method of protecting patient autonomy (by presenting a choice) and as a method of legally documenting it. However, I argue that these contemporary healthcare practices, while undergirded by a professed commitment to patient autonomy, may actually exacerbate the experience of suffering by failing to recognize and accommodate the essential relational components of patient identity that are crucial to the meaningful exercise of autonomy as well as to the provision of effective medical care (Chapter 7).

The final goal of this project is to engage in a brief exploration of the nature of suffering, its effects on the self, and the goal of medicine to relieve suffering (Chapter 8). I argue that suffering is a risk to identity, and loss of identity is a risk to autonomy. But relations to/with others can help to preserve or restore identity *and* autonomy and are fundamentally important in the context of suffering, especially when that suffering is related to a sense of self that is fractured due to a serious, ongoing, or life-threatening health conditions. Drawing on the work of Robert Veatch to illustrate my points, I argue that the current medical/bioethical paradigm assumes and promotes a type and level of patient autonomy that is difficult to achieve under ideal circumstances, and that is even

harder to achieve when patients are under the duress of pain or illness (Chapter 9). While I acknowledge the detrimental effects that paternalism and coercion can have (and have had) on patient autonomy, I argue that current efforts in medicine and bioethics to institutionalize respect for autonomy are both too zealous and too narrowly focused. I argue that the current preoccupation with ensuring that patients exercise independent choice and control over their healthcare decisions without being influenced by others sets an extremely arduous and unrealistic expectation that may have contrary effects than intended or expected—namely, that it may actually undermine providers' attempts to relieve suffering. To alleviate suffering, patients must be cared for in a way that respects and restores identity, which also promotes autonomy. This kind of respect, restoration, and autonomy comes from acknowledging and nurturing relationality in medical decision-making contexts.

## CHAPTER 1: KINDS OF AUTONOMY

Many variations of the concept of autonomy have been cultivated since the idea first took root in ancient Greece. From its origins in political theory, use of the concept has been adopted—and adapted—by scholars across a range of disciplines. Through their work, the term has branched out in many directions, making room for new interpretations and applications, and over time evolving into a number of distinct forms, such as legal, economic, or moral autonomy. Despite their sometimes pronounced differences, these variations maintain a close relationship with one another, owing in large part to their shared conceptual origins and the way that developments in one area or branch of autonomy have spurred reciprocal changes in the other areas. Given this, it may be helpful to think of “autonomy” as the family name for a set of related concepts that bear more or less of a resemblance to one another while also maintaining their own distinctive features.

However, because the concept of autonomy lends itself to such an abundance of interpretations and applications, it has also frequently become a source of contention. Disagreements between scholars within and across different areas of study, or amongst

policymakers, administrators, and citizens, often arise because, as Mackenzie and Stoljar note, “the *concept* of autonomy is sometimes conflated with one particular *conception* of autonomy and its attendant conceptions of choice and rights” (5, original emphasis). Even within a given thematic branch of autonomy, the idea can take on a multitude of forms or operational modes, including (but not limited to) being employed as an ideal, a descriptive concept, a norm, or a right. As such, the contours of the concept may shift, sometimes dramatically, depending on the circumstances of use, the specific scholarly tradition being referenced, and the work that the idea is being called upon to do.

In the United States, the concept of autonomy gained a strong foothold in the American imagination as early as the country’s founding, where is provided a strong political argument for the colonists’ separation from Britain. Since then, the idea has sustained continuous evolution, featuring prominently in both scholarly and public discourse and, in recent years, receiving a high degree of uptake in the form of “individual” or “personal” autonomy. This variation, which is the focus of this project, is perhaps one of the most complex variations to be born out of autonomy’s conceptual lineage (and which owes much to the other varieties that preceded it). It is typically characterized by its focus on the individual person as an independent agent with the authority to direct her life in the manner she sees fit. Since its debut, the idea of personal autonomy has become one of the most ubiquitously used and impactful offshoots of the

concept, due especially its strong resonance with the dominant traditional American values of independence, self-reliance, and individualism. As such, the idea of personal autonomy has thoroughly permeated the collective cultural consciousness and features prominently in contemporary discussions of identity, lifestyle choices, privacy, personal property, and medical decision-making. In order to better understand how this particular conception of autonomy came to enjoy such pride of place, I start at the beginning with an overview of the concept of autonomy as a whole and the way that developments across disciplines have led to its evolution into a variety of influential and distinct branches. Although a number of taxonomies of autonomy have been proposed, I will structure this discussion around the five categories identified by Diana Meyers, which I think adequately cover the breadth and nuance of the concept while also demonstrating the relationship and overlap between these conceptions.

### **Kinds of Autonomy: Political, Legal, and Economic**

Although the conception of autonomy that is best-known and most widely employed today primarily concerns the ability of an individual person to be self-directing with regard her private life (e.g. the ability to decide and act, without undue constraint, in ways that reflect one's own values, preferences, and goals), this particular use of the term, which is often referred to as "personal" or "individual" autonomy, is considerably far removed from its etymological roots. At its origin, autonomy (from Greek, literally "self-law") was a political idea. The self-government implied in the term

was representative of the way that emerging Greek city-states were beginning to organize themselves into independently functioning regional governments. Over time, the concept migrated outside of ancient Greece and grew to address larger issues of state sovereignty, especially with regard to international relations. In this context, the concept had very little to do with individuals except insofar as they can be understood as an aggregate unit for political consideration (e.g. as a “people,” “nation,” or some other group identity with political significance).

As a quality of sovereign nations or states, political autonomy is bound up with notions of independence (from the controlling influence of other states or entities), legitimacy (e.g. endorsement of a government’s effective authority over a people), and international recognition (e.g. other states or international actors recognize the legitimacy of the sovereign nation). But political autonomy may also encompass domestic concerns pertaining to citizens, such as the nature and extent of citizens’ political participation, the conditions under which citizens continue to give deference to the rule of law, and the legitimacy of a government’s claim to speak and act for (or upon) a particular people. In this sense, political autonomy is often tied to notions of liberty, democracy, and freedom from tyranny or oppression.

Political autonomy may also concern the quality and scope of the rights, restrictions, and opportunities afforded to citizens or groups through their government, although these latter concerns are sometimes identified with the related notion of “legal

autonomy.” While there is significant overlap between these two variations, the former is typically meant to indicate the realm of distinctly political activity, while the latter concerns aspects of the life of the citizen generally, irrespective of political involvement. Legal autonomy also brings a slightly greater consideration for the role of individuals, albeit in a generic and collective sense, with a general concern for defining the rights and responsibilities of individuals as citizens or other residents subject to the rule of law. The close relationship between the concepts of political and legal autonomy can be seen clearly, for example, in the Declaration of Independence, the first formal assertion of political autonomy by the newly formed United States. In this document, the authors claimed the right of self-governance and demanded the international respect and recognition necessary for the legitimate and independent function of their new government. At the same time, through the affirmation of the inalienable rights of all persons to “life, liberty, and the pursuit of happiness,” they also laid the foundation for the later recognition of the legal (and personal) autonomy of the citizens under its jurisdiction.

These commitments were further solidified through the adoption of the U.S. Constitution. In addition to codifying the governing principles of the new nation, the subsequent amendments demonstrated the government’s adaptive response to the call of its constituents for formal, legal recognition of the responsibilities and benefits of citizenship. As well as protecting a clearly defined set of basic rights, the Constitution



subsequently evolved, through variety of amendments and noteworthy Supreme Court cases, to offer additional protections for citizens as distinct individuals pursuing their own personal conceptions of the good ("the pursuit of happiness"). Thus, although the right of autonomy is not explicitly enumerated in the text, judicial interpretations of the "spirit" of these documents have frequently supported additional protections against certain types of coercion and exploitation that may impact the private lives and diverse life plans of citizens. This has included such rights as freedom of conscience and expression, the expansion of property rights to include not only physical possessions but also the idea of personal property in one's body or one's self, and the provision for equal protection of all citizens under the law. In contemporary medicine, in tandem with the right of privacy (another right derived from similar court interpretations), the implied right of autonomy has also been used to successfully defend patients' ability to make controversial medical choices and to protect patient access to medical goods and services, especially within the realm of reproductive health. In this way, these foundational documents designed to establish political and legal autonomy in the U.S. have also simultaneously buoyed the adoption of a certain conception of personal autonomy by safeguarding individual interests, promising liberties that bolster self-determination, and providing a strong basis for recourse against unjust infringements. Together, these constitutional rights protect individuals in a comprehensive way designed to enable citizens to live autonomously under the auspices of the law.

In a similar way, the category of economic autonomy also has significance at both the state/political level and at the citizen/individual level. In the former sense, it refers to the ability of a government to operate effectively without significant economic dependence on, or financial coercion from, other states; in the latter, it typically refers to financial solvency at the individual or family level, which also has significant bearing on personal autonomy. The degree of economic autonomy enjoyed by a nation or its citizens is also frequently in a reciprocal relationship with the degree of political and legal autonomy experienced by that entity. When nations are politically autonomous, they have more control over the cultivation and distribution of their domestic resources (e.g. a significant portion of the nation's wealth and other assets are not being transferred to another ruling power, such as under imperialism). Especially under the influence of capitalism, nations typically aim to manage domestic assets (including labor, natural resources, creativity/ingenuity, physical and intellectual imports/exports, etc.) so as to reduce dependency on foreign goods, cultivate beneficial trade agreements, maximize wealth, and consolidate political influence, thus maximizing efforts towards economic security and independence (autonomy).

This also usually entails efforts to mobilize a productive and competitive workforce, promote innovation, reduce levels of unemployment, and minimize or manage utilization of social welfare programs. As such, policies and programs designed to promote economic autonomy at the national level can also have a direct effect on the

economic autonomy of its citizens. For example, a nation that is interested in increasing productivity or gaining a globally competitive edge in industry or innovation may enact policies designed make it easier for companies to hire, train, or retain employees (such as tax breaks or incentives), use domestic capital to invest in programs that encourage productivity (such as educational subsidies or workforce development grants), and enact legislation that protects workers' rights (such as establishing fair hiring standards, family and medical leave, and short-term disability pay).

At the individual level, economic autonomy is often identified with financial self-sufficiency, which Diana Meyers argues may describe, "anyone who has a secure job that pays enough to sustain a satisfactory existence" to anyone who "need not depend on any other individual to supply their needs and desires" (12). This characterization draws attention to the fact that financial security typically corresponds with increased freedom and opportunities and is one of the bases of public (and self) respect. Thus, this type of autonomy raises particular concerns for individuals whose labor is unpaid or underpaid (e.g. women, undocumented workers) and for those who cannot participate in the labor market for reasons of inability, lack of appropriate accommodation, or lack of prerequisite education or experience (e.g. some people with low literacy, disability, or complex medical needs, the elderly, or people whose educational or career prospects were thwarted by poverty, debt, substance use disorders, or other psychosocial interruptions). Socially, a perceived lack of economic contribution (e.g. by not

participating in the paid workforce or the inability to secure a full time or higher status paid position) or the inability to demonstrate financial self-sufficiency (e.g. those whose primary or only means of subsistence comes from public welfare programs, alimony, or child support payments) may have severe consequences for individuals and their families, including social stigma, material deprivation, a limited range of opportunities, social isolation, and vulnerability to coercion and exploitation—all of which may, as I will later discuss, also have a deleterious impact on personal autonomy, both in general and especially in the context of medical decision-making.

Thus, especially in Western capitalist societies, political, legal, and economic autonomy are all strongly intertwined. While the discrete individual is generally not the focus when discussing or measuring the levels of autonomy experienced by a nation or its citizenry, together these concepts support a portrait of the “ideal autonomous citizen” as one who is fully vested in the widest range of benefits and opportunities available in a particular society, who makes a positive contribution to towards the nation’s economic goods, has financial resources commensurate with self-sufficiency, and is able to partake fully in political life. These qualities are also strongly correlated with personal autonomy, at least insofar as political, economic, and financial autonomy make it more likely that an individual will have the resources and protections necessary to lead the kind of life that is in line with her own particular beliefs, preferences, and goals.

## **Kinds of Autonomy: Moral and Personal**

Whereas the political, legal, and economic conceptions of autonomy tend to concern populations or groups in a general sense, it was with the development of the idea of moral autonomy that the individual person was introduced as the more salient unit of measure. Arguably, one of the most influential contributions to the idea of moral autonomy in Western philosophical thought is found in the eighteenth-century philosophy of Immanuel Kant. Kant's work was produced amidst an ideological shift in conceptions of morality away from natural law accounts that emphasized obedience to God's laws (as made known through revelation) and deference to religious authority (which left no room for individual reason or conscience), towards accounts that emphasized the capacity of the individual to discover the nature and demands of morality.

Kant argued that the moral law is objective and universal, and that it is made known by each person individually through the faculty of reason. Autonomy is a fundamental component of Kant's morality because it is both the basis and the result of proper reasoning. That is to say that a person can only discern the moral law if he has autonomy of mind, and he can only commit to the moral law if he has autonomy of will. Therefore, an autonomous person is *not* one who is free to choose his own moral principles, acting in a way that is most pleasing to him or that best resonates with the principles he has chosen to endorse. Rather, the autonomous person is one who is

bound by his own volition to the demands and constraints of the universal moral law (which is discovered but not decided by him). As such, he is both the author of the law (because it is discerned by his own rational faculties which originate inside himself) and the subject of it (because obedience is the only rational choice an autonomous person can make).

This self-same author/subject relationship to the moral law highlights the importance of the individual and also forms the basis for respect for persons. But while Kant's theory emphasizes that the individual person is significant on the basis of being a moral lawgiver, he is not significant on the basis of his *individuality*—at least not in the now widely accepted sense of irreproducible uniqueness. Since the law is objective and universal, all autonomous individuals use reason in the same way to arrive at exactly the same conclusions about what morality entails. Therefore, autonomy is not especially “personal” in the sense of being tied to any particular character trait or facet of personality. This link between autonomy and personal identity did not appear until much later, with the rise of another variation of the concept: individual or personal autonomy.

Personal autonomy, also called individual autonomy, is concerned not so much with the “impartial, universal obligations” (Anderson 5) that tend to characterize discussions of moral autonomy, but rather with how a person lives her life generally, both in her day-to-day concerns as well as over the course of her lifetime. The concept

of personal autonomy draws on related notions of identity, authenticity, personal choice, self-reflection, value commitments, and self-determination, amongst others, to show whether and how someone can be said to “be one’s own person,” “live by one’s own lights,” and “be true to oneself.”<sup>1</sup>

The concept of personal autonomy, especially as it relates to individuality, is often invoked in defense of choices or behaviors that may be perceived as unusual or unconventional. It is also frequently used as a justification for standing one’s ground when individuals feel that their choices or opportunities are being unduly threatened or constricted. This can be seen, for instance, in the vaccination controversy that has gained momentum in recent years. Because vaccines are so effective in reducing the transmission and/or morbidity of certain communicable diseases within populations, and because this has both individual and public health benefit, parents face considerable social and legal pressure to vaccinate their children. Frequent early childhood immunizations are considered routine preventative healthcare and many of these shots are legally required in order for children to be allowed to attend day cares or schools. Because there is a high degree of social uptake with regard to the validity of scientific and medical authority, social coercion in favor of immunization is not usually seen as a threat to personal autonomy. As such it typically does not result in resistance or dissent from most parents. However, there are a growing number of individuals who

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<sup>1</sup> These common expressions are referenced in explanations of personal/individual autonomy in a variety of sources, including work by Marilyn Friedman, Joel Anderson, Diana Meyers, and many others.

reject the immunization imperative on the basis of personal or religious beliefs, and who resist conformity with widely accepted vaccination schedules as a matter of personal autonomy. Despite facing public derision, difficulty in finding healthcare providers who respect their beliefs, and obstacles in securing education, childcare, and other opportunities for their unvaccinated children, many of these parents continue to oppose vaccination policies and practices that they feel coercively impinge on their right of refusal as individuals/parents.

Cases like this can also demonstrate the ways in which the different variations of autonomy may overlap and interact in ways that impact the whole person. Having a strong sense of oneself as a person (e.g. having an appreciable understanding of who one really is “deep down”) is an important component of personal autonomy. Without this understanding of the self, there is no meaningful sense in which a person can be said to be authentically self-governing. But personal identity is a complex and dynamic construct. It is stable and yet also continuously “in process.” It is durable, but responsive to a multitude of influencing factors both internal and external to a person. Hence, the unique constellation of beliefs, interests, relationships, commitments, and experiences that are constitutive of personal identity are bound to the factual circumstances of the person’s existence. That is to say that considerations such as where and when a person lives, the socioeconomic status she inhabits, the type of educational, financial, or legal opportunities available to her, or the basic moral requirements of her



society, are all relevant aspects of the other types of autonomy I have discussed that also come to bear on personal autonomy. This is because, as I will argue in this project, personal autonomy is fundamentally relational. This means it cannot be extricated from a person's social context, which includes many of those elements that are also relevant to the other forms of autonomy.

For example, in John Christman's account, personal autonomy is in a direct and reciprocal relationship with political autonomy. He argues that just political systems protect the personal autonomy of citizens, while autonomous citizens form the basis for the legitimacy and perpetuation of just democratic government. Similar reciprocal relationships can be found in other accounts of autonomy, such as Diana Meyers claim that, "The category of morally permissible actions... constitutes the orbit of [personal autonomy]" (15). From her perspective, moral and personal autonomy are bound together such that the former sets the parameters of the latter, restricting the exercise of personal choice to the bounds of accepted moral norms. In a like manner, other accounts have demonstrated how, under capitalism, economic autonomy correlates with a higher degree of personal and legal autonomy because the opportunities afforded by financial security enhance agency and may offer some protections against certain civil injustices and social inequities.

Returning to the vaccination controversy, then, we can see how the issue of parental refusal, as a matter of personal autonomy, also gives rise to considerations that

can span across the various categories of autonomy. Thus, while the decision of whether or not to vaccinate children may reflect particular personal preferences or lifestyle commitments, it could also be reflective of moral considerations (e.g. parental refusal on the basis of conscience or religious beliefs) or legal autonomy (e.g. refusal as a matter of principle, as a type of liberty protected by legal right)—all of which are affected by the corresponding degree of social or legal tolerance present in the society, to permit or disallow such deviations. Similarly it could also raise issues of financial or economic autonomy (e.g. as pertains to the increased financial burdens faced by parents if they are unable to send their children to daycare or public schools), or of political autonomy (e.g. as a matter of justice, with regard to living under the authority of a government that forces or coerces its citizens to undergo medical procedures against their will).

In this chapter, I have given an overview of the way the developments across a number of disciplines have resulted in the branching of the concept of autonomy into a number of distinct thematic areas. In the next chapter, I will provide a short overview of how theoretical and cultural developments, both within these thematic areas as well as across time and space, have been woven together over time to create the current picture of personal autonomy that is operational in bioethics and healthcare today.

## CHAPTER 2: THE FOUNDATIONS OF PERSONAL AUTONOMY

As I have begun to show, autonomy is a robust and resilient concept, capable of being adapted to myriad political, social, and scholastic purposes. Owing to its versatility, it has endured the test of time, gaining prominence even while weathering centuries of cultural change. At present, the concept is most widely recognized in the variation of “individual” or “personal autonomy,” which has grown to overshadow the other forms of the concept, even while incorporating many of their key elements.

In order to better appreciate how this particular expression of the idea became so integral to bioethics and the practice of medicine, it is helpful to examine the philosophical origins of the concept and explore the characteristic features it has acquired as it has evolved in relation to the other categories of autonomy and the distinctive influence of American history and culture. While it is outside the scope of this project to provide a complete historical topography of the concept, in this chapter I aim to provide a brief, selective sketch of the landscape, highlighting some of the most distinctive landmarks of the concept’s developmental trajectory. This includes drawing attention to the increasing significance of the individual in this picture, and the

attendant emphasis on individualism, security, property, and boundaries. The goal of this overview is to set the stage for a more thorough discussion of the benefits and limitations of the way that the legacy of this evolution continues to shape perceptions of the nature and value of personal autonomy, especially as it has been translated into contemporary bioethics and healthcare practice.

### **Ancient to Early Modern Foundations**

While its earliest Greek usage did not yet apply the concept of autonomy to persons, from the time of the ancient philosophers, there were seeds of individual autonomy germinating. As Mark Piper notes, there were many ancient philosophers who applied the related notions of self-mastery and self-control to individuals. They emphasized the importance of achieving balance and order in one's life, which was associated with greater personal freedom and higher states of excellence, by cultivating rationality and the proper equilibrium between the rational, passionate, and appetitive aspects of the person.<sup>2</sup>

In fact, in *The Invention of Autonomy*, Jerome Schneewind's impressive chronicle of the evolution of moral autonomy in the two centuries or so prior to the work of Immanuel Kant, he posits that Socrates kickstarted the whole endeavor of moral philosophy—from which the concepts of moral autonomy, and later personal autonomy

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<sup>2</sup> Socrates, Aristotle, Plato, and the Stoics, amongst others, are variously referenced on this point.

grew—with the fundamental question of how we ought to live.<sup>3</sup> Centuries later, prominent thinkers drew inspiration from the ancients as they sought to address that same question, in conjunction with the other pertinent moral questions of their day. As they advanced the areas of political and moral philosophy, their work also laid a foundation for later conceptions of personal autonomy with its attendant emphasis on reflection, self-reliance, and personal responsibility. For example, during the French Renaissance, Michel de Montaigne, taking Pyrrho and Socrates as his role models, developed a practical test for moral theories: namely, trying to practice what they preached. Montaigne believed that moral theories ought to be practical enough that the common person, not steeped in scholarly pursuits nor recognized as particularly wise or virtuous, would be able to follow them. Of Montaigne's practice, Schneewind writes,

He finds out what his deepest convictions are by trying simply to portray himself honestly over a whole lifetime. With Socrates he seeks to know himself: he himself must be the source of acceptable guidance... The self he portrays is the self as it can be understood by experience and reflection... (Schneewind 48)

Montaigne's perspective—that an average person could derive moral content (such as values and rules) from himself through reflection—stood in stark contrast to the received philosophical tradition of his day that emphasized obedience and deference to God and king. In this way, work like Montaigne's signaled a shift toward an

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<sup>3</sup> From Plato, *The Republic*, Book I, line 352d

increasingly secular interest in human beings' capacities for self-governance (Schneewind) and increasing emphasis on the primacy of the individual.

The idea in moral theory that human beings could use their own faculties to determine what morality required (as opposed to relying on revelation and/or a religious authority) was mirrored in political theory by the increasing focus on individuals' rights, and growing challenges to the justification and legitimacy of certain types of government. In the West, the idea that political or legal autonomy could pertain to individuals—and that the legitimacy of a government could be tied to the degree to which it recognizes and protects individuals' rights—first began gaining momentum in the early modern period. For instance, seventeenth century Dutch jurist Hugo Grotius is credited with advancing the idea of a “right” as a property of an individual. According to Schneewind, “He treats them as qualities grounding law, not as derived from law. They are personal possessions” (80). As such, individuals can do with their rights what they like—including alienate them. On this account, a primary sort of injustice is the violation of one's property (both possessions and rights). By framing the law and morality in terms of what an individual can and cannot do, and requiring others in society to respect boundaries concerning their relationships with other individuals, Grotius earned his reputation as “one of the founders of individualism” (Schneewind 81).

The prominence of the individual can also be seen in the work of Thomas Hobbes. In *Leviathan*, he gives an account of the origin of social cooperation and government that begins in the “state of nature.” In this original condition, every man is equal to every other man simply because they all have either the strength or the ingenuity to kill one another. In Hobbes’ depiction, each man is motivated exclusively by his own interests, especially the interest of preserving his own life (which is understood as a basic natural right). But, as Garrath Williams explains, in this state, “We do not just have a right to ensure our self-preservation: we each have a right to *judge* what will ensure our self-preservation.” Especially in the context of insecurity, judgment about what may be necessary to ensure continued existence is highly variable, and is not infallible. In these precarious circumstances, a person may determine it necessary to lie, cheat, steal, or even kill in order to secure his interests, because the failure to act swiftly, defensively, and decisively may have disastrous consequences.

Thus, facing severe violence, insecurity, and constant terror (the war of all against all), individuals—understood foremost as “natural rights bearers”—had no choice but to enter into social contract with one another, since this presented the greatest chance of achieving peace and self-preservation. So, on Hobbes’ account, political order arises not from any sort of natural inclination towards fellowship or cooperation, but rather from the collective agreement of self-interested individuals to

give up a significant portion of their natural rights in order to establish a government that can offer some basic protections as well as mete out justice.

Arguably, in Hobbes' explanation of the origin of government, some individuals gave up a greater proportion of their natural rights than others in order to benefit from the social compact. In the state of nature, all people may have had the opportunity to be heads of households and sovereigns, but certain disadvantages (such as lack of strength or intelligence, or vulnerability due to age or the physical realities of childbearing) made them susceptible to being overpowered. Since natural law prevented individuals from forfeiting their own lives, those who were unable to prevent being conquered became the subjects of their captors. Their subsequent submission to this authority, although coerced by survivalist motives, is construed on Hobbes' account as consent to this particular kind of social contract. Thus, the most vulnerable individuals in the state of nature have no other choice than to become the subjects of their conquerors in the form of "wives" and "servants." As Hobbes writes, "For it ought to obey him by whom it is preserved; because preservation of life being the end, for which one man becomes subject to another, every man is supposed to promise obedience, to him, in whose power it is to save, or destroy him" (140).

Hobbes' portrait of humankind, both in and out of the state of nature, supports the view of the individual as a self-interested, solitary figure. As Elizabeth Wolgast argues:



In Hobbes's picture of equal autonomous agents, people can be likened to molecules of gas bouncing around inside a container. Each molecule proceeds independently, is free to go its own way, although it occasionally bumps into others in its path... No atom helps or moves aside for another; that wouldn't make sense. They are a collection of unrelated units. (3)

In leaving the state of nature, men became individuals in compact with one another and were united under the absolute power of the sovereign, thus granting some security and protection of their interests—although this did not totally extinguish the fear or threat of other people. Even when joined through the commonality of citizenship, individuals remained somewhat detached and guarded.

This account highlights the increasing significance of the individual as demonstrated by the shift from the belief that the sovereign rules by divine right to the idea that the sovereign rules by the will or consent of his subjects. Hobbes' account also reflects the enduring, pernicious belief that there are compelling reasons (particularly those owing to the "natural" differences between people in terms of strength, intelligence, etc.) that explain and justify differences in social status and exclusion from the rights and benefits of citizenship. What is interesting on Hobbes view is that individuals' ongoing endorsement of the sovereign's authority was not necessary to maintain rule. The original consent of the people secured the sovereign's position such that if a sovereign ruled inadequately or tyrannically, citizens nevertheless owed their

obedience to him by the terms of the original contract. Since other social arrangements (notably marriage) were seen as similarly contracted, this also helped to explain and justify the continued subordination of women and other oppressed groups during this time.

Later social contract theorists rejected Hobbes' attribution of absolute power to the sovereign, instead placing more weight on the rights of individuals and the importance of ongoing consent in establishing the legitimacy of a government. In John Locke's picture of the state of nature, people are equally endowed by God with certain rights, specifically rights to those things that make continued existence possible (life, liberty, health, and property, as well as the right to justice for violations of these). Using reason, individuals are able to recognize that they, as well as others, have rights such as these and that they should not be violated. One particularly influential and enduring idea from Locke, introduced in his *Second Treatise on Government*, is the notion that "every man has a property in his own person" (§ 27) <sup>4</sup> and that he acquires further property rights to those things that are available to all in common if he expends effort (either his own, or the effort of his servants or employees) to acquire or improve them. Thus, unlike in Hobbes' state of nature where the threat of other people hampers social cooperation, on Locke's account, individuals are able to interact civilly with one another

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<sup>4</sup> This idea was foundational for later developments, especially in bioethics, concerning rights and autonomy. In particular, this conception of the body as a special kind of property protected by rights to privacy and against interference became the basis for arguments against paternalistic, nonconsensual, or otherwise exploitative medical care and research.

and thus are able to cooperate in order to develop community goods (such as a bartering economy).

Nevertheless, these theories do account for the fact that violations still occur, and in the state of nature, it is up to the wronged individual, or his representative, to proportionately punish the offender(s). Unfortunately, the ability of a wronged party to determine for himself what it means to judge impartially and punish proportionately can itself be a source of error and injustice. Ultimately, then, rational individuals see the need for a government, formed by the consent of the people, to protect their rights, arbitrate over disputes and exact justice. As this is the primary function of government—to recognize and enforce individuals' rights—if a government fails to do this, Locke says that the citizens may dissolve it. This understanding of rights (especially property rights), the significance of the individual, the purpose of government, and the idea of government by consent became hugely influential in the deliberations that led to the development of the nation and government of the United States.

### **The Influence of Kantian Moral Autonomy**

The time from the Scientific Revolution through the end of the early modern period was marked by drastic changes in scientific, philosophical, and social thought in Europe. One of these changes was the increasing confidence in the rational faculties of the individual and, by contrast, a growing distrust of uncritical deference to authorities.

In the essay, "An Answer to the Question: What is Enlightenment?" Kant laments that individuals have been cosseted, and ultimately stunted, by their unwillingness to fully utilize their minds, instead preferring guidance and encouragement from others. As previously discussed, rationality and a certain sense of individualism were integral components of Kant's moral philosophy. In that essay, he likens those who fail to use their capacity for reason to "placid" and "dumb" domesticated animals, afraid to take a step without the direction of their masters' yoke or bridle. From Kant's perspective, this is a serious fault because to be directed by anything other than one's own mature, rational mind is to be heteronomous—a condition he viewed as unacceptably debasing. To be heteronomous is to live as livestock rather than as persons, because what it means to be fully human is to be autonomous, and to be so in the most fundamental way: as one's own moral lawgiver.

From Kant's perspective, the call of the Enlightenment was for individuals to reject servility and instead contribute to the tide of progress through the employment of reason and trust in one's own capacity for self-direction. Kant's frustration with those who failed to utilize reason and preferred to maintain their "self-incurred minority" extended broadly to "the greatest part of humankind (including the entire fair sex)" ("Enlightenment" 17). It was not necessarily that they lack the capacity, he argued, but rather they lack mettle and appreciation for the value of independence of the mind. This immaturity was, from Kant's perspective, sufficient justification for limiting the social

and political role of those who failed to achieve this level of autonomy (women and other minorities especially). For example, in *The Metaphysics of Morals*, Kant identifies children, servants, and “all women” among those “whose preservation in existence (his being fed and protected) depends... on arrangements made by another,” and who therefore lack “civil personality” (458). This dependence, which Kant viewed as diametrically opposed to autonomy, explained their inferior status and justified the denial of citizenship, education, and other opportunities.

But while social, economic, and gender inequality formed the basis for denying the “civil personality” of some groups, Kant nonetheless claimed that all people are equal in human dignity. It is rather that this dignity does not translate into equal privileges for all people, so that some individuals enjoy “active citizenship” while others have “passive citizenship,” or are, rather, mere “associates of the state” (*Metaphysics of Morals* 458). Kant writes that to be a citizen,

The quality requisite to this, apart from the *natural* one (of not being a child or a woman), is only that of *being one's own master (sui iuris)* hence having some *property*... that supports him—that is, if he must acquire from others in order to live, he does so only by *alienating* what is *his*... (“On the Common Saying” 295, original emphasis)

In arguing that it is necessary that one not be a woman or a child in order to be a citizen, Kant seems to clearly support maintaining the subordinate position of women who, by

his explanation, are not autonomous. We also see in this excerpt an emphasis on property, especially possession of property as a means for both staking a claim to political consideration and for securing privacy and independence from others that was quite common at the time. Women, being the dependents of their fathers or spouses, lacked property rights, and therefore had no basis for independence, autonomy, or citizenship. This was similarly true for those men who worked under the tutelage of others or who did not control the means for producing property, such as serfs and apprentices.

This idea of dependency as a basis for exclusion from the social contract reflects some of the same assumptions and arguments prevalent in Hobbes, Locke, and their contemporaries' political work nearly a century and a half earlier. It is also an idea that has clung tenaciously to the concept of autonomy even into the present day, where vulnerability and reliance on the care of others continue to be treated as conditions that are antithetical to autonomy. As a result, people who are perceived to have greater dependence on the support or care of others than is considered socially desirable or tolerable are more likely to face discrimination, loss of opportunity, and other hardships that further diminish recognition of their status as autonomous agents. Especially in the context of medical decision-making, the consequences of this can be detrimental.

However, Kant also writes that the laws adopted by those with the privilege of active citizenship cannot contradict "the natural laws of freedom and of the equality of

everyone in the people... namely that anyone can work his way up from this passive condition to an active one" (*Metaphysics of Morals* 459). By this caveat, Kant leaves open the possibility that those in lesser social positions, such as children, the poor, and perhaps even women, might have the possibility to "outgrow" their subordination and join the ranks of active citizens. This idea, too, has had a strong and long-lasting influence on subsequent thought about the nature of autonomy. This is especially true in the United States where ideas such as "the self-made man," "pulling oneself up by one's bootstraps," "coming up from nothing," and working one's way to success and prestige (such as the idea that any given child could grow up to be president) are popular and persistent cultural tropes.

### **Autonomy in the United States**

Around the same time that Kant was contemplating these questions of morality and autonomy in Europe, across the ocean, legislators in the newly forming United States were debating the essential principles of their new government. Influenced by the work of John Locke, the framers of the U.S. Constitution felt a special resonance with his focus on property as a primary right of individuals. In the framers' minds, issues of liberty, property, and security were inextricably bound together. For those early settlers who came willingly to the "New World" (i.e. those who were not sent as debtors, prisoners, or slaves), religious freedom and economic opportunity were the primary motivations for making the voyage. For some expatriates, settling the new territory

offered some the chance to put a vast oceanic buffer between themselves and the religious intolerance and persecution they left behind. But overwhelmingly, the promise of abundant space and natural resources that needed only to be claimed and tamed enticed new arrivals by the thousands, increasing the wealth not only of those settlers of entrepreneurial spirit, but also of the government that sponsored them.

Over time, however, those well propertied British citizens living and working in the American colonies grew increasingly disenchanted in their relationship with the British homeland. The battle cry of “no taxation without representation” reflected the settlers’ increasing frustration with the proliferation of levies imposed upon them by the British parliament. As such, this slogan encapsulated one of the major grievances that the founding fathers charged against the king at the start of the Revolutionary War. These taxes were seen by the founding fathers (many of whom were members of a well propertied, privileged minority) as a violation of their rights and a threat to their prosperity. Already feeling vulnerable because of their lack of proximity to the old country (which had previously provided infrastructure, social and legal support, and opportunities for political involvement), settlers’ anxieties were multiplied by difficult environmental conditions and the prospect of violent conflict with native peoples or foreign nationals from other territories. As a result, during the colonies’ separation from Britain, the founders became increasingly concerned with protecting their holdings from encroachment or seizure, either by the state or by their neighbors. Part of what



they required from a new government was the liberty to manage their property as they wished, and effective protection of both that liberty and the property itself.

In Jennifer Nedelsky's critique of the relationship between autonomy and property in U.S. constitutionalism, she argues that the framers inordinately privileged the interests of property holders, using property as a persuasive demonstration of the tension between the minority and the majority (or citizens and the government) that the framers feared and tried to mediate. One way of remedying this tension was to use rights to draw a line around the individual that others and the government must not cross. Thus, rights could be seen as insulating and protecting individuals within the private spheres of their property (both the property of their own bodies, as well as their external possessions) from intrusion and other unwanted interactions. This approach highlights the perceived need for the individual to maintain positive separation from others who may wish to do him harm. As such, Nedelsky argues that property became both a metaphor and a concrete example of the freedom that the framers were trying to establish and protect.

This correlation between property and privacy also had some interesting ramifications for the evolution of the concept of autonomy. With this focus, the framers portrayed property rights as an exemplary demonstration of what it means to be an autonomous citizen—that is, to have the liberty to have and do with (and on) one's property as one wishes, to retreat into one's property to escape the demands of social

life, and to defend one's property against encroachment and breach by others. Property and privacy are closely related in their connotations with secrecy (a shield from the prying eyes of others or the government), seclusion (away from the public sphere), and protection (as in their expectation of an impervious boundary around the individual and the sphere that the individual controls). In setting up the principles and protections of their new government, the founding fathers posited "boundaries as the means of comprehending and securing the basic values of freedom or autonomy" (Nedelsky 162).

These ideas have continued to inform the way the body, and hence bodily autonomy, is understood in culture and medicine in the present day. For example, the body continues to be viewed as a special kind of personal property whose boundaries are defined through the organ of the skin. Even the immediate area surrounding the body has come to be understood as "personal space," an invisible buffer between the body of one individual and the body of another. Breaching this space is a social taboo that can result in profound discomfort for the affected parties. But medicine, by its very nature, must at times encroach on personal space, going even so far as to breach the boundaries of the body. Privacy in this context concerns who may view the body, which parts, and under what circumstances. For example, during a physical exam, placing a drape over the parts of the patient's body that are not being examined is meant to reduce patients' feelings of exposure and vulnerability by symbolizing the clinician's respect for bodily privacy through the act of voluntarily limiting the scope of her gaze

to only that which is immediately necessary. By contrast, when providers act upon the body without patient agreement (e.g. by resuscitating a patient with a known “Do Not Resuscitate” order), even if the action would have normally been within the scope of the provider’s expected duties, this is viewed as a legally actionable transgression of patient autonomy.

### **Other Late Modern Contributions**

As social and political theory continued to evolve, the tension between the individual and others, or between the individual and the state, remained a salient issue. We see this clearly in John Stuart Mill’s essay, “On Liberty,” in which he writes:

[T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others...

In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.

(50-51)

In this passage, Mill affirms personal autonomy (if not explicitly by name, then surely in spirit) as a matter of both legal and moral right. Mill argues that in order to establish political order, some constraints on individuals’ “personal impulses and preferences” (Mill 102) may be warranted; but having accomplished this aim, his concern is that the pendulum of social control may swing too far in the opposite direction, jeopardizing the rights of individuals who dissent from public opinion or deviate from social norms.

Insofar as these “eccentrics” do not cause harm to others, Mill advocates tolerance, arguing that, “the amount of eccentricity in a society has generally been proportional to the amount of genius, mental vigor, and moral courage which it contained” (109). In this respect, a parallel can be drawn between Kant’s concerns about servility and herd mentality, and Mill’s concerns about governmental control and social conformity undermining reason, stifling dissent, and ultimately trampling individual liberty.

Mill’s contributions to the concept of personal autonomy are seen clearly in his emphasis on character and individuality. Whereas for scholars like Kant, Hobbes, and Locke, individuals are important in a generic, somewhat interchangeable way, Mill finds value precisely in a person’s distinct *individuality*. He writes, “In proportion to the development of his individuality, each person becomes more valuable to himself, and is therefore capable of being more valuable to others... it is only the cultivation of individuality which produces, or can produce, well-developed human beings” (Mill 104-105). Mill argues that the act of conscientiously deliberating and making choices<sup>5</sup>—rather than blindly following the dictates of custom or popular opinion—engages and strengthens the mental faculties necessary to develop character.

Also noteworthy is the fact that Mill’s work clearly places women within the camp of individuals who are capable of cultivating these qualities. In *The Subjection of Women*, he argues that women’s subordinate position in society is the result of

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<sup>5</sup> This emphasis on independent, rational deliberation followed by choice is extremely pervasive in the dominant conception of patient autonomy active in healthcare today.

convention and coercion, not natural inferiority. He writes, "What is now called the nature of women is an eminently artificial thing—the result of forced repression in some directions, unnatural stimulation in others" (Mill 503). It is the same obstacles—the caprices of culture, restrictive social conditioning, and unchallenged prejudices—that produce lack of character in both men and women and result in increased susceptibility to heteronomy. Conversely, when a person's "desires and impulses are his own... are the expression of his own nature" (Mill 102), it demonstrates strength of character. Such a person has cultivated the faculties necessary for self-directed, deliberative action and is less vulnerable to being compromised by coercive outside influences. As such, he is more likely to stand by his convictions in the face of dissent and better able to resist the tyranny of both unjust government and of the majority. Thus, on Mill's account, character and individuality are personal properties that turn out to have considerable social and political significance. As the idea of the value (and actual possibility) of democratic government began to gain favor in the West, the importance of the individual also began to increase in proportion. This change in political consciousness concerning the role of the citizen as an individual (especially as an agent and rights-bearer) also provided strong legal and social support for the germinating contemporary conception of personal autonomy.

### CHAPTER 3:

#### THE IDEAL OF AUTONOMY

In addition to its evolution into different categories of autonomy, within each category, the concept can also operate in a variety of distinct but related modes. These modes, like the broader categories themselves, represent an array of creative ways that the concept of autonomy has been adopted and transformed through its long history of interdisciplinary scholarship in constant interplay with diverse medley of social and cultural influences. Because they are underpinned by slightly different assumptions, commitments, and goals, each of the possible modes brings different elements of the concept of autonomy into focus. For example, within the category of individual or personal autonomy, one way of highlighting the concept's versatility is to contrast the "ideal of autonomy" and "descriptive autonomy," on one hand, with "normative autonomy" and "autonomy as a right" on the other. This bifurcation highlights the difference, as Joel Anderson puts it, between "what gets you autonomy" and "what autonomy gets you" (1).

To illustrate the differences between these modes, consider, for example, the case of some eighteen-year-olds in the United States—particularly those who are still

enrolled in high school, who reside with and are financially dependent upon their parents or guardians, who are not responsible to any significant degree for the decision-making in their households, and who are generally inexperienced with regard to many of the conventions and responsibilities of adulthood. While these newly minted adults may not yet fit the commonly accepted criteria of descriptive autonomy—and may fall considerably short of ideal autonomy—they are nonetheless normatively autonomous in this society (e.g. they are owed the same respect for their decisions and lifestyle choices as any other autonomous person). This is because the presumption is that, upon reaching the age of majority (if their competence is not otherwise limited by significant mental disability or some other hindrance), they are capable of assuming full responsibility for themselves, both legal and otherwise. As such, they are recognized as having certain rights aimed at protecting their autonomy (e.g. having privacy and sole discretion in medical decision-making), and in general, are taken to be the sorts of individuals who are capable of directing their lives as they see fit without significant outside direction or restriction. Nonetheless, depending on the particulars of their lived experiences, they may be more or less proficient in the exercise of the capacities necessary for achieving ideal autonomy. Therefore, when talking about individuals who fit this characterization, depending on what we wish to emphasize or argue, we may have equal grounds to say that: they are autonomous; they are not autonomous; they

are potentially or minimally autonomous; or, that they have certain rights of autonomy. Thus, further elaboration is warranted concerning what each of these modes entails.

In the next few chapters, I will describe a few of the distinctive features of these four modes of personal autonomy—all of which have had an active role in shaping how patient autonomy is understood and exercised in medical contexts—in order to better understand differences in perception of the merits and shortcomings of each particular usage. I will begin in this chapter with an exploration of “autonomy as an ideal” since this instantiation sets the bar for what personal autonomy is—or should be—in its highest or best form, and has significant bearing on the way the concept is expressed in the other three modes. In this discussion, I will examine how the contemporary legacy of the historical developments discussed at the beginning of this project have become increasingly problematic, leading some scholars to question the utility of continuing to promote such a seemingly flawed and potentially harmful model of personal autonomy.

### **Autonomy as an Ideal**

To understand autonomy as an ideal, it is important to identify what distinguishes an ideal from a less weighty or ordinary goal or objective. Kimberley Brownlee describes an ideal as “a model of an advanced state, excellence, or perfection around which we can orient our attention and seek to effect substantial changes in perspectives and practice” (116). An integral component of this idea is that an ideal



represents an admirable or desirable state, one that is worthy of the commitment that a person makes to it. By extension, the ideal of autonomy tells us what autonomy is and should be in its highest or best form, and sets the bar for autonomous persons and actions. Represented as an ideal, the value of autonomy is presupposed.

Brownlee argues that there are four primary features of ideals: comprehensiveness, aspirationality, constitutive cultivation, and unrealizability. When someone holds an ideal, it becomes an important, pervasive, and deeply rooted part of that person (comprehensiveness). Because of the integral part it plays in that person's life, and because of how highly she esteems it, she continually turns her attention to it and strives toward its fulfillment (aspirationality). Furthermore, the orientation one has and the actions one takes toward an ideal are "to varying degrees constitutive of that ideal itself and not merely an independent, instrumentally useful means for pursuing it" (Brownlee 120). For example, if a person truly wishes to become a world-renowned surgeon, then this ideal will call for the adjustment of a variety of aspects of her life, including perhaps giving up other lesser goals in order to better orient herself toward this accomplishment. The professional and educational opportunities that she pursues will not only have an impact on how likely that she is to achieve this ideal—they will also actually be a part of the process of achieving it. That is because a person cannot be a world-renowned surgeon without, for example, completing the appropriate education, having the opportunities to practice the art of surgery, and accumulating the experience

necessary to develop proficient medical judgment and expert surgical skill. Striving toward these things is part and parcel of both the pursuit and the attainment of the ideal. Striving is an essential element of ideals that speaks to their worthiness or value; it is also the process that familiarizes an individual with the requirements of the ideal and prepares her to achieve it.

In order for ideals to have this aspirational quality then, they must also include an element of unrealizability—at least in the short term. This fourth component of Brownlee’s definition manifests itself in a variety of ways. Some ideals are unrealizable because they require an attitude or orientation that is unsustainable (e.g. they will accept nothing less than a level of perfection that is not humanly possible). Others are unrealizable because they look toward an event or objective that cannot currently be achieved (e.g. the ideal is outside the limits of any currently known human capacity). Still others are unrealizable because they are “ongoing progress ideals” where “[t]here may be no upper bound... or, even if there were, that bound may lie beyond the present abilities” of the person striving toward it (Brownlee 123). And it is on this basis (the unrealizability condition) that the ideal of personal autonomy is commonly criticized.

### **Criticisms of the Ideal**

Some scholars have argued that the ideal of autonomy is defined in such a way that it is actually impossible for some individuals to ever attain it; as such, it is unjust to hold individuals accountable to an ideal that is intrinsically exclusionary to them. For

example, as a child, I aspired more than anything to be a Catholic priest. It was a vocation that I held in very high esteem and it featured prominently in my early childhood imagination and spiritual development. But, as Brownlee points out, there is clear difference between ideals that are “presently unrealizable” (123), and those that are conceptually impossible. With regard to my childhood ambition, I had to reconcile with the fact that unless something fundamental about what it means to be a Catholic priest changes, there is simply no possibility of me ever achieving this goal. As a woman, fulfillment of the ideal of entering the Catholic priesthood is inherently inaccessible to me, even though it remains attainable for many men who aspire to it. Therefore, it would be oppressive to live in a society that was oriented around the expectation that I would continue to espouse, as a personal ambition and value of mine, the ideal of entering the priesthood. Though the goal might be comprehensively integrated in my life through my aspiration, I would not be able to make significant progress toward it no matter how fervently I strived to cultivate the required attributes. It is simply not accessible to me.

Similarly, there is a concern that there is something inherent in what it means to be autonomous that makes it conceptually impossible for some people to ever achieve or even approximate this ideal. As a result, it is more difficult for some persons than for others to live in a society that is oriented around a specific, limited characterization of autonomy and the expectation that it is (or should be) universally valued. This

expectation presupposes a problematic level of homogeneity in the values, experiences, needs, and opportunities of most people. Hence, using the ideal as the bar for measuring competence, securing the rights of citizenship, recognizing personhood, or any other similar weighty human concern may result in the oppression of those persons or groups who are systematically excluded from the possibility of recognition as autonomous agents.

As some philosophers argue, the way that the ideal of autonomy is typically presented (as a universal ideal, protected in the language of rights, with the implication that it is descriptively accurate to classify most adults as autonomous and morally obligatory to treat them as such) represents a privileged way of being in the world. As Peggy McIntosh has persuasively argued, certain identities or affiliations confer an “invisible knapsack” of unearned social assets on group members. These assets include increased opportunities, greater social respect, legal and/or physical protection, and other myriad perks that promote a general sense of possibility and belonging. The key to this metaphor, however, is the way that this inequitable benefit-conferring system is meant to operate *invisibly*—that is, under the radar of those being disproportionately advantaged.

Unrecognized privilege, as a naturalized condition, makes it difficult for some individuals to identify and appreciate the significance of inequality and oppression. As

Susan Sherwin argues, it also has a considerable impact on conceptions of autonomy.

She writes,

[P]eople who were raised in an atmosphere of privilege and respect come rather easily to think of themselves as independent and self-governing; it feels natural to them to conceive of themselves as autonomous. Having been taught that they need only to apply themselves in order to take advantage of the opportunities available to them, most learn to think of their successes as self-created and deserved. (25)

Hence, the persons most likely to be concerned with the ideal of autonomy are those whose life circumstances have led them to have the reasonable expectation that it is both valuable and achievable. But not all socioeconomic conditions, social or familial environments, or cultural or personal values are compatible with autonomy as traditionally conceived. To achieve autonomy as it is typically characterized requires not only time and mental capacity, but also the financial means, physical security, and minimum level of social standing (including social respect) to secure the life opportunities conducive to this pursuit. People whose primary concern is subsistence, or whose opportunities and choices are seriously constrained by oppression, exploitation, or other pervasive obstacles like material deprivation, may find it difficult to be self-directing in the way that the ideal of autonomy implies.

Accordingly, critics argue that the dominant tradition prescribes a mode of autonomy that does not resonate with the experiences of people in marginalized or minority groups, and instead presupposes a particular, privileged sense of identity and way of being in the world that is inaccessible to many. Rather than considering themselves the beneficiaries of unequal power systems or the lucky but undeserving winners of the natural lottery, privileged individuals tend to see their experiences as normal and their privileges as earned. They expect that others experience themselves as autonomous agents in the same quality and degree as they do. They feel largely “in control” of their lives, and fail to recognize that, “the self’s control of the self...will be circumscribed by the ways in which our lives are shaped *for* us and not *by* us” (Christman *Politics* 10, original emphasis). As a result, Sherwin argues, they see their own more favorable circumstances as the product of deliberate choices they have made in the pursuit of opportunities that were available to everyone. This allows them to dismiss the disadvantages and hardships of those in marginalized groups as the result of poor executive function, moral failing, or lack of foresight, rather than the result of systematic inequality.

One way that disparities in privilege can translate into disparate experiences of patient autonomy is through inequality of opportunity. Consider, for example, two patients with the same life-threatening condition (e.g. a refractory form of bone cancer) who have both have exhausted all currently available treatment options. The only

remaining chance of therapeutic benefit is through an investigative new drug that has not been approved for use in their condition. Since neither patient is eligible to receive the drug through participation in a research study, their treatment teams appeal to the pharmaceutical company to request permission for emergency use compassionate access, and the company agrees. The only caveat is that cost of one standard course of treatment costs greater than \$150,000 per patient (not inclusive of related supportive care costs such as examinations, blood tests, infusion costs, etc.), and neither patient's insurance plan will cover this expense because the drug is considered experimental. As a result, both patients must pay out of pocket if they are to receive the treatment. In these circumstances, owing the particulars of their upbringing and current social standing, one patient may be much better able than the other to take inventory of her available assets and opportunities to leverage them against the cost of care. One patient may, for instance, have an inheritance or a retirement account that can be liquidated. She may feel secure in her ability to dip into these assets because her level of education and/or professional specialization affords her job security and adequate future earning potential to replenish her savings. On the other hand, if the second patient does not have such personal resources or social assets, then her only choice may be to forfeit this option for care. As a result, the former patient enjoys a much greater (current and future) level of personal autonomy than the latter patient, owing particularly to the opportunities associated with her more favorable social standing.

But even if it is not the case that the ideal of autonomy is intrinsically exclusionary, the typical ways that progress toward (or attainment of) the ideal is defined and measured (both socially and legally) may create additional barriers to recognition and inclusion of some persons or groups. Because of the prevalence of the assumption that personal autonomy operates in certain predictable ways across all (competent) individuals, when persons diverge from expectations, the implication is there is good reason to question their rationality, competence, or independence. This raises important questions about how to or how to judge individuals' capabilities, obligations, and liberties when their status as autonomous agents is unclear (for example, in the case of children, people who are developmentally disabled, or those with advanced dementia). I will return to these practical concerns, which align more closely with the descriptive approach to autonomy, in the next chapter.

A different line of criticism posits that the problem with the ideal of autonomy is not that it is *intrinsically* exclusionary per se—although the aforementioned critique of the ways that the ideal is used to justify excluding some persons from the benefits of recognition as autonomous agents still stands. Rather, it is simply that autonomy as an ideal is undesirable and not genuinely valuable in itself, or that it promotes or requires the cultivation of some qualities (e.g. individualism, detachment, self-interest, etc.) to a degree that is not desirable or valuable.



Consider again how widely treasured the concept of autonomy is and how deeply it is woven into the fabric of American society. This is evident in the country's dominant socio-historical narrative, which is punctuated by key events and achievements that demonstrate the country's admiration and commitment to the ideal (e.g. the fight for independence, Westward expansion, the Civil War, the civil rights movement, etc.). At the national level, commitment to the ideal has undergirded domestic policies, shaped the country's reputation, and set the tone in international relations. At a personal level, it has set the bar for the conduct that is legally and socially expected of citizens, promoting such qualities as self-sufficiency, financial independence, assertiveness, and responsibility. The correlation of this expectation is that individuals take on increasing legal freedoms and obligations as they begin to meet the criteria for recognition as autonomous citizens (e.g. those typically associated with age, such as driving, voting, conscription, entering into contracts, consuming alcohol, etc.). Because of this relationship, many people have great confidence that appeals to their self-determination and inviolability have weight, as demonstrated in assertions like, "it's my life," or "my body, my choice," or "nobody has a right to tell me what I can and can't do with/on my own property."

But as we have seen, even from the founding of the country, not all persons were originally meant to be included under this umbrella of protections. As previously discussed, the Declaration of Independence and the Constitution are two of the most

recognizable documents that underpin citizens' autonomy in the United States. Written in broadly inclusive tones, these documents codified the "universal" values (and attendant legal benefits and protections) that have defined American citizenship for generations. Yet, the dissonance between the universal ideals expressed in these texts and the historical reality of the time at which they were written cannot be ignored. While these documents promised a certain level of recognition and protection of autonomy to *all* citizens, given the particular vantage point of the framers, it turns out that qualification for citizenship (and thus autonomy) was reserved for a deliberately small portion of the population.

As a result of the history discussed in Chapter 2, the traditional picture of personal autonomy that has emerged from this foundation is characterized by individualism, disembodied rationality, emphasis on property, space and boundaries, and overarching self-interest. In response to fear and insecurity, the view of autonomy that has emerged is preoccupied with constructing (metaphorical or actual) barricades aimed at protecting autonomy through separation. Some feminists argue that this kind of boundary imagery, rife with connotations of militarism and violence, is very stereotypically masculine in its formulation. As such, they argue that it is incompatible with those qualities typically associated with femininity, such as relationality, embodiment, emotionality, and sublimation of self. As Mackenzie and Stoljar explain, "traditional conceptions of autonomy not only devalue women's experience and those

values arising from it, such as love, loyalty, friendship, and care, but are also defined in opposition to femininity” (9).

The concern here is that this way of being “other-oriented,” where one’s physical and emotional connections with others are a constitutive element of personal identity, is fundamentally at odds with the ideal of autonomy as previously construed. As Linda Barclay argues, “The relationship of parent to child, the traditional conception of what it is to be a wife, or caring for a frail and aging parent can hardly be characterized as a form of cooperation for the efficacious pursuit of self-interest” (59). Rather, many aspects of individuals’ lives and identities are built around important relationships, and they are often willing to sacrifice some of their own interests for the sake of these relationships. And in fact, many of our most valued relationships are grown and sustained in close quarters, where space is shared, boundaries are blurred, and where vulnerability and dependence add depth and intimacy to those connections by creating opportunities for care and trust. In recognition of this, Nedelsky (drawing on Starhawk) offers an alternative boundary image that sidesteps some of these criticisms: the human skin, which she describes as, “permeable, slowly and constantly changing while keeping its basic contours, and a source of sensitive connection to the rest of the world” (176). This kind of imagery retains a sense of individuation and difference that has positive value while also drawing out the myriad (and less confrontational) ways that persons are meant to experience themselves in relation to others in the world.

But this type of relational imagery is not popularly associated with the ideal. Rather, the traditional conception construes such other-oriented persons as so cognitively and emotionally encumbered by their relational commitments that it closes off the possibility of autonomy. As a result, individuals who conceive of themselves in this relational way may never be able to cultivate those qualities necessary to achieve personal autonomy as traditionally defined—or at least not without substantial sacrifice and remodeling of their values to a degree that jeopardizes their authentic sense of self. In essence, under the traditional conception of the ideal, being so wholeheartedly invested in these relationships makes such individuals heteronomous.

In the current framework of medical decision-making, this other-oriented form of subjectivity is seen as particularly problematic. Because there is a legal and ethical obligation for providers to secure patient's informed consent for care, there is a pressing need to be able to be reasonably certain that a patient is, in fact, capable of independent deliberation and choice, and that her decisions are truly her own. However, when patients base their care decisions on considerations of the needs and preferences of others—or when they refuse to make any care decisions without the agreement and acquiescence of another party such as a parent or spouse—this is typically viewed by providers as a red flag that the patient is not autonomous. As Inge van Nistelrooij et al. explain:

For if a professional caregiver repeatedly hears the patient mention these other persons' perspectives ("but my mother still needs me", "my daughter will get married in four months", "my successor is not yet ready to take over my business"), she may be tempted to ask: "But what do you want yourself?" This question expresses that the patient's relations can be (temporarily) put aside in order for the patient's individuality to come to the fore. (642)

In these circumstances, the expectation of the traditional conception of personal autonomy is that an individual will somehow be able to extricate her "true" self from the obscuring influence of her relations to/with others in order to arrive at an autonomous decision. Thus, the inability to separate one's identity from the influence of one's relations (often expressed as an inability to "set boundaries") is seen as strong evidence of a lack of autonomy.

One possible response to criticisms of this kind (i.e. that the ideal is exclusionary, whether intrinsically or in its effects; or that the ideal is not genuinely valuable; or that it is incompatible with other more desirable values) is simply to ask: is that a critique of autonomy or of something else? Or, to put it another way, are those problematic descriptions, qualities, or effects constitutive of the ideal or are they merely correlated with it? For example, Marilyn Friedman challenges that "despite superficial resemblance," ideas like self-sufficiency, independence, selfish egoism, etc., do not "seem to be distorted substitutes for an ideal of personal autonomy. They seem to be

distinct notions" (*Autonomy* 48). Mackenzie and Stoljar have offered a similar reply, claiming that what is being objected to by these sorts of critiques is not the philosophical notion of autonomy, but a caricature of it that has taken hold in popular culture. Thus, by a series of skewed associations in the collective imagination, over time the popular understanding of autonomy has become something that most serious academics did not, do not, and would not endorse.

But even if the characterization of personal autonomy that is most common today is based on misunderstanding or misrepresentation of the ideal, that explanation does not, by itself, remedy the problem. Whether it is a true portrait or a bad reproduction, how the ideal of autonomy has traditionally been represented and deployed (historically, socially, institutionally, etc.) has certainly had some real and persistent adverse effects in the lives of many individuals. Like barnacles, those objectionable characteristics associated with the ideal have clung on tenaciously over the centuries. While a robust conception of autonomy can certainly withstand a few hapless associations, the apprehension is that so many of these troublesome attachments have been growing so closely to the concept for so long that they have become intricately entwined with in it. Therefore, it is important to investigate whether the concept has been wholly corrupted by the company it keeps (and consequently has ceased to be valuable or useful) or whether it can and should be reformed.

## **Procedural vs. Substantive Accounts**

To better understand the qualities and values that have been associated with autonomy in more critical philosophical accounts, one can start with the differences between procedural and substantive approaches. Examining the way that such values do or do not operate in these approaches may help to highlight where philosophical accounts of personal autonomy may diverge from the way the concept has popularly been received.

Procedural approaches identify some process or set of conditions that must be met in order for a person to be considered autonomous. Typically they specify the presence (and exercise) of certain mental capacities or intellectual properties such as “non-contradiction, minimal coherence, and basic mental competence” (Anderson 8), and often require some sort of hierarchical process of higher level reflection on lower level desires to ensure that one really does endorse them (Dryden). If these requirements are met, procedural accounts are open, without normative constraints, to the full range of values and choices that a person may endorse or pursue. This type of approach may permit individuals to pursue self-interest, individualism, and other such qualities as have become associated with the concept, but it by no means requires them. This type of account may define the requirements of autonomy both neutrally and minimally so that most individuals would count as autonomous (at least for a portion of their lives, such as in adulthood) by these baseline criteria.

One concern for procedural accounts, however, is that the requirements may be too generic to capture the richness (and thus the value) of the concept. Some critics claim that by only requiring a basic cognitive process be followed in order for a person to be considered autonomous, the value of autonomy is undermined. As Willard Gaylin and Bruce Jennings argue, procedural autonomy “has no inside; it is an empty freedom waiting to be filled with choices... [It] also has no direction, no purpose beyond itself. It is the freedom to choose and the activity of choosing that matter, not what is chosen” (36). Their criticism is that in being as open and accessible as possible to the widest variety of interpretations and value commitments (within the basic procedural requirements), the concept of autonomy itself becomes less meaningful. As such, it has little to differentiate it from other concepts like agency, choice, or simple procedural independence.

Yet, while some may criticize procedural autonomy for being an “empty” concept, others argue that such accounts actually fail, in a subtle way, in achieving the content or value neutrality that they purport to endorse. They argue that some procedural accounts actually assume and privilege a specific understanding of the self, and that this has normative implications. As Joel Anderson explains, the self that is operable in many hierarchical, procedural accounts is the model of detached or disembodied rationality (as derived from Kant), which is taken to be universal. However, such “ideal” or “universal” formulations of a concept (such as rationality in



this case) are rarely able to achieve neutrality because they are still conceived from a particular historical, cultural, and personal vantage point and the limitations of this must be taken into account. A more recent example of this type of ‘unsuccessful neutrality’ can be seen in John Rawls’ *A Theory of Justice*.

Although not concerned with personal autonomy per se, Rawls’ work depends on a certain, universal understanding of the self (including a certain conception of autonomy) as it pertains to individuals’ ability to rationally determine the principles of a just society. Rawls’ theory is based on a thought experiment called “the original position,” which functions as an alternative to the “state of nature” political origin story discussed in Chapter 2. Individuals in the original position find themselves behind a “veil of ignorance” that masks their identities—both from one another and from themselves. Any knowledge of the particulars features of themselves (such as nationality, race, gender, age, era, intelligence, strength, political or religious affiliations, or any other aspect peculiar to identity) is excluded, including “natural assets and abilities” (as pertains to the experience of embodiment) and “special features of psychology” (Rawls 118). Participants are further characterized as “rational and mutually disinterested” (Rawls 12), and they are socially isolated from one another in so far as, “they are conceived as not taking an interest in one another’s interests” (Rawls 12). According to Rawls, this also makes them disinclined to altruism, which implies that social relationships operate outside the scope of rationality.

Participants may assume that, outside of the original position, they do actually have these particularities, but the effectiveness of the experiment depends on the possibility of separating individuals' rationality from all other features of their personality or lived experience. Hence, participants are expected to deliberate as identically anonymous bearers of pure rationality—with the implication that considerations of embodiment and social embeddedness would only serve to adulterate the process. In essence, Rawls proposes to erase these factors from the equation because they do not (or should not) bear on questions of justice. As Rawls writes, "the veil of ignorance deprives the persons in the original position of the knowledge that would enable them to choose heteronomous principles" (222). Thus, detached rationality—which stands apart from the attenuating influence of relationships, social context, and the general features of lived experience—is highlighted as a characteristic of autonomous individuals that promotes successful deliberation about the requirements of justice.

But the feasibility of being able to accurately imagine not having any personal or unique attributes whatsoever is questionable. Even the language of our innermost thoughts is a product of our social context that colors the way we are able to think about things (i.e. language influences reason).<sup>6</sup> Therefore, even as a thought experiment, the original position is a difficult basis for deliberation. Furthermore, in Rawls' theory, each

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<sup>6</sup> This thought comes to mind in relation to Gerald Dworkin's statement that, "It makes no more sense to suppose we invent the moral law for ourselves than to suppose we invent the language we speak for ourselves" (36).

deliberator's motivation for choosing certain principles stems in large part from the desire not to be unfairly disadvantaged once identities again become relevant. So at the same time as the self is supposed to be as generic as possible and more-or-less absent from consideration, there is also a sense in which self-interest is driving the deliberations (but, problematically, without a full picture of what "self" actually entails).

The problem persists even when Rawls argues that the thought experiment is not strictly necessary, and that, "To say that a certain conception of justice would be chosen in the original position is equivalent to saying that rational deliberation satisfying certain conditions and restrictions would reach a certain conclusion" (119-120). And this is where Rawls' claim mirrors arguments often found in procedural accounts of personal autonomy: namely, in the assumption that rationality operates in certain predictable ways across all (competent) individuals, and that some form of "rational deliberation satisfying certain conditions and restrictions" (where those conditions are, of course, spelled out in more detail in such accounts) is all that is needed in order for persons to be autonomous. But this response does not really address the concerns of whether those "conditions and restrictions" are actually content- or value-neutral, given the reality of being situated in a particular social context that sets the criteria for neutrality or objectivity. And in practice, when the results of individuals' deliberation

diverge from expectations, the implication is that there is reason to question whether they are rational (and therefore autonomous).

By contrast, substantive accounts hold that personal autonomy is incompatible with the endorsement of certain values or desires, or that autonomy requires certain value commitments or “self-regarding attitudes, such as self-respect and self-esteem” (Stoljar “Feminist Perspectives”). Without the appropriate moral or psychological orientation, a person would fail to be autonomous on a substantive account even if she were capable of making choices and acting volitionally as is minimally required on procedural accounts. The difference between procedural and substantive accounts is frequently demonstrated by reference to the circumstance of “voluntary slavery.”<sup>7</sup> On a procedural account, it is possible for a person to autonomously choose to relinquish her autonomy (provided that this person/choice meets the procedural requirements), whereas on a substantive account, this is not a desire or a choice that is compatible with autonomy. In the latter case, by “choosing” slavery (which is an obviously autonomy undermining circumstance), a person demonstrates that she does not have the appropriate value orientation to be considered autonomous; therefore, choosing slavery cannot ever be a validly autonomous decision.

In healthcare, some demonstration of personal autonomy on the part of the patient is typically a necessary condition for providing consent and other legal decision-

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<sup>7</sup> Those who discuss the idea of “voluntary slavery” in the context of procedural vs. substantive autonomy include: Joel Anderson, Marilyn Friedman, Marina Oshana, Mark Piper, and Natalie Stoljar, among others.

making. In the United States, healthcare organizations work within the parameters of the law to establish minimal procedural standards (such as appropriate age, mental competence, and the provision of informed consent) for ensuring that patients are able to make autonomous medical choices. These standards aim to reduce medical paternalism, avoid influencing patient decision-making in ways that may be perceived as prejudiced or coercive, and protect providers and institutions from legal liability. And for the most part, these policies support a neutral conception of patient autonomy that permits decision-making based on a wide range of possible patient values.

In the best-case scenario, patients are provided with relevant information about the currently available and medically appropriate options. They are given time to deliberate and discuss these options with their providers or loved ones, and then they are free to choose the care that best aligns with their preferences, values, and treatment goals. However, institutional or provider commitments to a procedural approach to autonomy can falter when patients make seemingly unorthodox decisions that are perceived to be against their own best interests, such as refusing lifesaving treatments, acting contrary to medical advice, or deferring or deflecting decision-making authority over their own care. Circumstances like this cause tension for providers who are stuck between a commitment to patient autonomy (which proscribes paternalism) and fidelity to their own judgment (as derived from their specialized medical expertise and experience) and concern for patient harm. In these circumstances, depending on the

perceived stakes of the case or the extent to which the patient's reasoning diverges from accepted medical opinion, patient autonomy may be called into question on a more substantive basis—namely that the patient seems to lack the requisite comprehension, rationality, or self-regarding attitudes to be considered competent to authoritatively exercise choice in that circumstance.

This can complicate the matter of how to respond to patients who otherwise meet the conditions of (procedural) descriptive autonomy since providers and institutions must decide whether to intervene against the patient's wishes or to wash their hands of responsibility in the event of adverse consequences of patient choice. The latter option is epitomized by the widespread medical term “against medical advice” (AMA), which is often appended to patients' charts as a protection against liability. Thus critiques of this kind indicate that there may strong reason to question not just the rationality or competence of individuals in cases like this, but also the limitations of the preferred (procedural or substantive) conception of autonomy.

## **CHAPTER 4:**

### **RELATIONAL AUTONOMY**

In recent decades, some scholars have been working diligently to distance “autonomy” from the inadequate and harmful representations that many critics claim have marred it over the years. Proponents of a newer approach, relational autonomy, attest that the ideal of autonomy is still genuinely valuable and warn against dismissing it out of hand based on the unfortunate caricatures and unfavorable associations it has accumulated over time.

In this chapter I will present the (relatively) recently developed “relational approach” to autonomy as a promising remedy to the criticisms that have been levied against the traditional conception. I will use the relational approach to discuss how the ideal of autonomy, thus reconceived, can be used to restructure the concept’s operation in other modes and circumstances. I argue that reframing the concept of personal autonomy to shift the dominant emphasis away from individualism, self-sufficiency, and boundaries makes room for a greater appreciation of the role of vulnerability, dependence, and relationality in identity formation, and thus, in the development and exercise of personal autonomy. This, in turn, can have a positive impact on the way that

personal autonomy is translated into practices designed to respect and promote “patient autonomy,” which may also improve the patient experience and help healthcare providers more effectively relieve suffering.

### **The Relational Approach**

Relational autonomy is a specific way of conceptualizing personal autonomy that aims to replace other more traditionally atomistic representations of the idea. Much like the other kinds/types of autonomy I have discussed, rather than identifying a single perspective, the term “relational autonomy” functions more like a banner under which a variety of related but diverse accounts can rally (Mackenzie & Stoljar). While all of them emphasize the importance of a range of social relationships in a person’s development and exercise of autonomy, the difference in the significance attributed to these relationships is the primary distinguishing feature between accounts that are “conceptually” or “constitutively relational” versus those that are only “causally relational.”<sup>8</sup>

In causally relational accounts, the fact that individuals are in relationships and are socially embedded is understood as the context or “background conditions” of personal autonomy (Baumann). These external social circumstances are recognized for their ability to augment or undermine the development and exercise of personal

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<sup>8</sup> This way of categorizing relational approaches is common. Some theorists who employ this distinction include: John Christman, Andrea Westlund, Natalie Stoljar, and Holger Baumann, among others.



autonomy, but they are not taken to be an intrinsic part of what it is to be autonomous. That is to say that under difficult or oppressive personal or social circumstances, it may be more challenging for a person to be autonomous (and some may fail to be), but these circumstances do not, by themselves, negate the possibility. This approach is open, then, to the possibility that an individual may overcome restrictive or autonomy-undermining conditions through creativity, perseverance, or some other collection of personal characteristics or mental states.

By contrast, constitutively relational accounts contend that a social connections and context are so integral to the very definition and exercise of autonomy that in the absence of certain necessary external social factors or relations, autonomy is not even possible. As Andrea Westlund summarizes this approach, “autonomy is a matter not just of what goes on in an agent’s head but also of ‘what goes on in the world around her’ ... To be autonomous, an agent must (among other things) enjoy a significant range of viable options and retain authority over her social circumstances” (28). Thus, constitutive accounts entail that an individual must have not only the appropriate personal or “internal” orientation (usually defined in terms of specific required mental states, capacities, or processes of reason) in order to be autonomous; she must also have the appropriate social or “external” orientation, which pertains to the nature of her relationships, her social status, and other features of her social milieu (Baumann).

To illustrate the difference between these two approaches, consider the case of child marriage in the United States.<sup>9</sup> Marriages where one or more parties are minor children are permitted in nearly all U.S. states if there is parental or judicial permission, or if one of the parties to the marriage is pregnant (Le Strat et al.; Tsui et al.). Of the states that allow it, most either do not specify a minimum age for participants, or the marriageable age is set below the legal age of sexual consent in that state (“Falling Through the Cracks”). Although more than seventy percent of these unions eventually end in divorce, minors who attempt to leave their marriages are typically unable to find adequate social support services (such as shelters that will take them and their children, career and legal services, etc.) because they are considered “runaways” under extant laws; they are also, due to age, unable to legally initiate divorce proceedings on their own behalf (“Falling Through the Cracks”). For children who find themselves in these circumstances, there is an increased incidence or risk of certain repercussions, including: domestic abuse, sexually transmitted diseases, cervical cancer, poverty, unwanted pregnancy, pregnancy termination, pregnancy complications including death, mental health issues, substance use disorders, and more (Le Strat et al.; “Falling Through the Cracks”).

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<sup>9</sup> Data on child marriage in the United States is very difficult to find. Based on available data collected from 41 states (with not all counties within those states providing data (at all, or within the full specified time frame)), between the years of 2000-2015, at least 207,459 minors were married (Tsui et al.). The overwhelming majority of these minors were girls, 34% of whom were aged 16 years or younger (Tsui et al.).

As Fraidy Reiss argues, minors in these situations usually face significantly restricted opportunities from an early age, including: lack of a complete, comprehensive (or even minimum) education; lack of job skills or experience; no access to a legal form of personal identification (such as birth certificate, license, or passport); no access to reliable transportation; no personal financial assets of any kind; and no social connections to anyone outside their immediate (often closed) communities. Even after reaching the legal age of majority, for such individuals, attempting to leave these marriages may result in the forfeiture of family, religious, or community support and recognition (such as being shunned, which Reiss identifies as a form of “honor violence”) and is very likely to result in the loss of custody of any children (Reiss).

Most adherents to the constitutively relational approach would argue that the minors (and young adults) who find themselves in these forced marriages cannot, under these circumstances, be autonomous. Their social circumstances and relations are so pervasively restrictive that they are simply not conducive to the development or exercise of autonomy. Unless something fundamental about their social context changes, they will continue to lack the degree of control over their situations that is necessary to act with authority in their lives. By contrast, while most causally relational models would recognize that such circumstances are not favorable for autonomy, there are at least two ways that a person in this situation could be considered autonomous despite such restrictive or oppressive external factors. First, the person could

reflectively endorse her current circumstances, seeing her subordinate position and lack of opportunities as appropriate to her role in her family and community, and this role could be an integral part of her personal identity and life narrative that she does not disavow.<sup>10</sup> Such a person could entertain the idea that alternatives are possible and yet believe that the current circumstances reflect her own values and goals, and that to live otherwise would cause her to feel alienated, where in this case, alienation represents “not simply a lack of identification... [but] feeling constrained by the trait and wanting decidedly to *repudiate* it... to reject it and alter it as much as possible, and to resist its effects” (Christman *Politics* 143-144, original emphasis).

The second possibility for autonomy under a causal approach is that the person could, in fact, wish to repudiate her marriage and the attendant circumstances in which she finds herself, and therefore resist it to whatever degree is possible. In this situation, the resistance that she undertakes is both protective and an essential element of her autonomy. As Holger Baumann argues,

She can retain her autonomy while being in contexts that are inimical to autonomy. But she cannot stay in such contexts forever, for then she will lose [sic] her autonomy. This can be explained by the fact that we need to stand in diachronic and dynamic relations to other persons in order to be capable of adapting to changing environments, of engaging in self-exploration and self-

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<sup>10</sup> This idea of “reflective endorsement” is popular in the literature and is often first attributed to Harry Frankfurt.

definition, of imagining alternative possibilities, of distinguishing legitimate expectations from those that are not, and of emancipating ourselves from particular persons or environments. (466)

Baumann's way of addressing the question of personal autonomy in such cases relies on an understanding of the person's agency over time, as it ebbs and flows over her life, which he calls a diachronic approach. Viewed in these terms, Baumann argues that a person can exercise autonomy through consistent effort to develop or strengthen the competencies required to have or regain authority over one's life. Therefore, while a person may not look autonomous if we extract one static moment of her life for analysis, she may nonetheless be autonomous if we look at her life diachronically.

Whether constitutive or causal, adherents to the relational approach argue that it is superior to traditional conceptions of autonomy because it emphasizes the centrality of individuals' relationships and social commitments and the impact these have on identity formation. However else it is characterized, the relationship between the individual and society is understood as one of interdependence, not merely of conflict. Relational accounts do not require the sacrifice of the individual, or of individuality, for the good of the community. Rather, there is still room for the individual to flourish, but "in a space negotiated with others" (Hague 50), where relationships promote

autonomy, instead of (only) detracting from it.<sup>11</sup> This recognition enables a more accurate and comprehensive exploration of the way that individuals understand themselves in (and in relation to) the world, and what impact this has on their values, choices, and goals as they pursue authentic and meaningful lives.

Advocates of relational autonomy are not blind to the problems that have attended the concept of autonomy (and its myriad uses) over the centuries. They agree with criticisms that the dominant conception can be used in ways that promote individualism and self-interest to a degree that undermines other social values and is detrimental to individuals, relationships, and communities. They recognize how the concept has been used in ways that are harmful, marginalizing, and exclusionary, and they understand the skepticism that some people have about the benefit of continuing to promote such an ideal. But their conclusion is that the concept can be reformed—and that it is worthwhile to so.

For instance, Mackenzie and Stoljar claim that most theories of autonomy don't actually presuppose individualism, although, to those theories' detriment, they may be guilty of giving insufficient attention or weight to relationships and social influences. Friedman has argued that liberal conceptions of autonomy don't require individualism, although she says that they allow for persons to autonomously choose to (try to)

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<sup>11</sup> I include this "only" caveat because relational accounts generally do recognize that not all relationships are positive or beneficial or ought to be preserved. Some relationships (and this term is used very broadly here) do undermine autonomy.

express themselves this way. And Ros Hague has argued that there is a useful distinction to be made between individualism and individuality. With this distinction, Hague says that the latter should be conserved even while the former is rejected, because individuality is an important component of developing one's identity, and the ability to define and cultivate an identity that fits oneself is a tool for combating oppression.<sup>12</sup> Friedman makes a similar point about individuation versus individualism, arguing that although emphasizing differences, separation, and individualism can be a source of exclusion and oppression, the inability to recognize and appreciate differences within and across groups, as well as between individual persons, can be equally problematic. As such, she endorses some individuation while rejecting individualism.

Therefore, relational approaches represent an effort to salvage the valuable aspects of autonomy from the dominant tradition in order to repair and restore the concept's reputation and use it as a tool to promote a wider range of representative values. Supporters argue that the appropriate (relational) understanding of autonomy can actually be used as a tool to mediate the perils of individualism, remedy exclusion

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<sup>12</sup> Hague draws an analogy between cultivating a personal identity, which she relates to autonomy, and Hegel's ideas of cultivating and claiming personal property that has some interesting implications. Thus Hague's approach, which emphasizes property and boundaries as important components of autonomy, stands in stark contrast to Nedelsky's work, which suggests that property and boundary images are not useful for thinking about autonomy.

and combat oppression.<sup>13</sup> As Friedman argues, a remodeled relational conception of the ideal “gives us a normative standpoint for critically assessing oppressive social conditions that suppress or prevent the emergence of autonomy” (*Autonomy* 19). For example, Meyers draws on the work of Simone de Beauvoir in *The Second Sex* to show how feminine socialization from early childhood on hampers women’s ability to achieve the same level of autonomy as men under the traditional conception of the ideal. Although Meyers takes issues with some of de Beauvoir’s claims about what is desirable about autonomy or what it requires (de Beauvoir seems to endorse the kind of individualistic, masculinist ideal of autonomy that relational theorists reject), she nonetheless sees de Beauvoir’s work as a strong and persuasive evidence for the detrimental effects of traditional gendered socialization that relational approaches aim to address.

Of course, as I have discussed, restrictive gender socialization is not the only factor that can constrain a person’s autonomy (or development thereof). Poverty, prejudice, violence, exploitation, lack of meaningful opportunities, and other forms of oppression seriously undermine people’s ability to be autonomous. Relational approaches aim to show that a complex web of institutions, rules, social attitudes, people, and life experiences affect the development and exercise of autonomy, and that a person’s social situation can be more or less conducive to these goals. Proponents

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<sup>13</sup> This is individualism in the sense of selfish egoism, not in the sense of individuality (as it relates to personality/unique identity).



assert that recognition of the relational nature of autonomy can be a basis of both self-respect and social respect. It helps to give structure, context, and meaning to people's lives since it encourages them to see themselves not as isolated individuals but as "persons in relation" (Macmurray). This approach helps persons to better understand themselves, which in turn helps them to imagine the possibilities for their lives and pursue them. It recognizes that relationships can provide support and encouragement for individuals and help them to become active shapers of their identities and their futures, rather than feeling lost, isolated, alienated, or overpowered by a sea of outside influences and pressures. As I will discuss in the next chapter, many adherents to this approach also emphasize the usefulness of thinking about autonomy in terms of competencies, stages, or degrees of development. In so doing, we can recognize the ways and extent to which people *are* autonomous, even if they have not (yet) achieved full flourishing autonomy, and thus avoid making sharp distinctions that segregate people into "autonomous" and "not autonomous" categories, which would bring oppression full circle.

### **My approach**

The understanding of personal autonomy that I endorse is deeply relational. It is tied to a particular understanding of identity (i.e. one's sense of one's "self" in the world) that is fundamentally dependent on connections with others. It entails that, whatever the realities of these social connections or relationships may be (e.g. whether

fleeting or enduring, nurturing or cruel, intimate or distant...), they are an essential component of what it means for an individual to be the “self” that she is. My account offers an interdisciplinary (and perhaps somewhat eclectic) perspective on identity and self that emphasizes the vital importance of other people and one’s social context to the development and exercise of autonomy.

This relational way of understanding “identity” and the “self” is expressed in Ubuntu philosophy and culture by the saying that “a person is a person through other persons” (Shutte).<sup>14</sup> This maxim represents the idea that humanity (in all the richness that term implies) is not possible in isolation, because connectedness to others is the motif that underscores our entire lives. This can be seen, for example, at the most rudimentary level in the fact that an individual owes her very existence to at least two primary connections: first, to two other persons who are not herself, who existed before her, and whose relationship to one another (whatever its nature) is the reason that she “is” at all; and second, to the relationship between herself and the person(s) who chose, from the start of her life, to take on the responsibility to ensure her continued existence. Thus, relationships to others have an impact on the individual even before she is born or can begin to have an awareness of what it is to be a “person” in the world (Nistelrooij et al).

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<sup>14</sup> Chuwa argues that English translations of the principles of Ubuntu, usually expressed in maxim form, do not capture their full meaning. To provide the best possible representation, he offers the following variations for consideration: “I am because you are; I am who I am because you are who you are; I am because we are; a human being is a human being because of other human beings; a human being is a human being because of the otherness of other human beings” (110).

But even beyond the physical relationships implied by the basic facts of generation and subsistence, from the start of her life, an individual not only exists, but actually becomes a “person” because of—and through—her caregivers and those others to whom she is connected, who act as the stewards of her personhood. It is through her caregivers that she is named and becomes a subject; it is through her community that her presence in the world is legally documented and recognized (Nistelrooij et al. 642). It is by her caregivers’ introduction that she is made known to others, and it is through their diligent care that she is preserved and nurtured during an expanse of time when she is particularly helpless and vulnerable. As she develops in consciousness and maturity, she finds herself already embedded in a web of relationships to/with others.

Understanding these connections helps an individual to orient herself in the world. As Leonard Chuwa explains,

Ubuntu recognizes the fact that an individual can only become conscious of his/her existence along with its rights as well as obligations towards the self, other persons and the universe by the medium of the presence of others. In other words, cut off from all others, no individual personal life is possible. (15)

Expressed another way, in terms of narrative identity rather than communitarian political philosophy, Paul Ricoeur argues that the “otherness” of other persons is constitutive of identity or selfhood. He argues that this is “not (or not merely) the result of comparison” but that “the selfhood of oneself implies otherness to such an intimate

degree that one cannot be thought without the other, that instead one passes into the other” (Ricoeur 3). Both of these approaches speak to the essentially relational nature of identity and human ‘being’ in the world. Through others, an individual learns how she is perceived and what is expected of her; and, conversely, she begins to refine her perceptions of others and adjust her own expectations. She begins to understand the particularities of her own social context and the unique opportunities and challenges it entails. She learns to examine the value of her connections and begins to choose some of her own affiliations and to reject others. As she matures, she begins to take on more responsibility for the development and preservation of her own “self,” negotiating her identity in the context of her relationships and experiences.

Understanding identity in terms of this relationality can promote a shift in the way we understand our connections to others, and therefore in how we conceive of personal autonomy. As Nistelrooij et al. argue, “we may be used to think [sic] of our relations as things that we ‘have’. But Ricoeur’s philosophy transfers this relational connectedness (including the tensions that are involved) from the outside to the inside of the self” (642). I argue that employing this way of thinking can help us to reimagine the current preoccupation with individualism, property, and boundaries that has become so much a part of the traditional conception of autonomy. These connections to others do not stand apart from us, at the outer bounds of our selves, as if static possessions that we electively claim or own in some way (e.g. *my* spouse, *my* children,

*my family, my Church, etc.*). Rather, these connections are a dynamic part of what it means to actually be (or become) our selves; they are incorporated into our selves as essential elements. Thus, as Nistelrooij et al. argue, this changes the focus from 'having' relations to 'being' in relation (e.g. from *having* a spouse, children, family, or Church community to *being* a spouse, parent, family member or a part of a Church community).

But this way of being in relation to others is not only constitutive of the self; it is also constitutive of the community. In other words, *being* a spouse or a parent is the disposition (fortified through action) that is required to make and sustain a family. This is the same way that, in Catholic theology, the Catholic Church understands its existence: namely, that the 'Church' is not the building in which the ritual of the mass is performed; rather it is the people of faith in their union with one another through God, regardless of temporality, space, or infrastructure. In Ubuntu, this idea can be expressed as, "I am known, therefore we are" (Chuwa 26), which recognizes that a person only exists because of her relationships with those in her community, but that the community also exists because she is in these relations. So individuals are beings whose identities are (at least partially) constituted by their social context; and they, in turn, are (at least partially) constitutive of the social context in which they (and others) find themselves. That is to say that being a "person" (in the sense of having personality, personal identity, or a sense of "self") is possible only insofar as an individual increasingly comes to understand herself through reciprocal relationships with other

persons; such a social orientation is a necessary (albeit not sufficient) condition for both community and personhood.

This way of conceiving of the relationality of the self and the constitution of the community also has some interesting ramifications for individuals when their connections to others are not so robust. For individuals who have few connections, or who experience the loss of an important connection, the effects can be quite damaging for both identity and autonomy. For example, when someone goes from being a daughter to being an orphan, this change can suddenly and fundamentally restructure her experience of herself in the world. Likewise, when someone's experience of herself is shaped by a lack of stable or vigorous connections to others (such as the experience of a child who is shuffled between foster homes or who is living in uncertain circumstances due to caregiver addiction), this can be autonomy threatening. As Friedman is correct to point out, "relationships of certain sorts are necessary for the realization of autonomy whereas relationships of certain other sorts can be irrelevant or positively detrimental to it" (Friedman *Autonomy* 95). Indeed, the relational approach does not claim that all connections to others are positive or beneficial. Some relations, of the right sort, are required for autonomy; but all relations, of whatever sort, can have a greater or lesser impact on personal identity. Therefore, while some connections to others may help a person to develop autonomy competencies, others may give rise to

the occasion to exercise autonomy competency through efforts to lessen the impact of harmful relationships by distancing oneself from them.

This approach also changes the traditional implications for what we owe to others that was formerly based on our level of proprietary interest in that affiliation. If we shift away from thinking in terms of 'my' relation, where 'my' designates a sense of ownership or responsibility for that possession in some respect, then this also changes our orientation toward those individuals who would have, traditionally, been 'not my' relation (and perhaps, then, 'not my' problem). For if one's is both a product and an essential component of her own social context (which includes a diversity of relations both proximate and remote, intimate and superficial, etc.), then it is not as easy to extricate oneself from social responsibility. If I am a reflection of others (through my identity, as constructed through these relations), and others are a reflection of me (because I am one of the 'others' who make up the context in which their identities are constructed), then it is much more difficult to stand at a distance from others and the pertinent issues of social justice that require my attention without experiencing some dissonance or discomfort.

Being in relation to others entails accountability in some sense, where accountability implies a self that is willing (normatively, if not actually) and able to take responsibility for one's conduct or influence on others. This idea is strongly related to speech insofar as accountability is, literally, the ability to give an account (which is then

often construed as *speaking up, speaking for, or speaking out*), and effective speech requires an audience of some kind. Hence, accountability in our relations entails occasions that may necessitate interpersonal dialogue. We can see this in the manner in which we hold someone accountable for her actions in court of law. In that circumstance, we offer that person and the party she has harmed the opportunity to give testimony to the facts of the interaction and to its impact, and this ritual is formalized through its legal documentation and witness by others. We can also see this relationality in Ricoeur's narrative account, where, as David Pellauer explains, "one is a self as one self among other selves, something that can only be attested to through personal testimony or the testimony of others." In this sense, giving an account of oneself or others is an important part of both constructing and recognizing one's self in all its relationality.

This idea of accountability as an important part of the self, and therefore of autonomy, can also be seen in Andrea Westlund's work, which she considers constitutively relational but procedural, and dialogical in nature. Westlund agrees with the basic premise of most procedural accounts—namely that, regardless of an individual's preferences or value commitments, there are certain formal conditions that must be met in order for that person to be considered autonomous. But while these accounts make reference to appropriate internal deliberative processes of some kind, Westlund argues that they typically miss their mark by setting the bar either too high (by requiring all "action-guiding commitments" to have been thoroughly examined and



endorsed by the agent) or too low (by only requiring that a person *would* endorse them *if* she examined them). Instead, Westlund posits that what is required for a person to be autonomous is “a certain kind of self-relation... in which she holds herself answerable, for her action-guiding commitments, to external critical perspectives” (35). Her account is therefore constitutively relational because this self-relation requires an openness to dialogue and a willingness to provide an account of oneself *to others* in response to (legitimate) inquiries or challenges. I am persuaded by Westlund’s arguments that this element of giving an account of oneself to others is critical to autonomy, as it is related in important ways to self-control and personal responsibility, as I will discuss in the next chapter (with respect to the development and exercise of autonomy).

Hence, my own perspective on personal autonomy is constitutively relational. Simply put, one’s social context and the connections one has to/with others are ineluctable components of personal identity that impact the development and exercise of autonomy. Personal identity is a dynamic but durable construct, composed of the myriad definitions, characteristics, affiliations, values, and aspirations one has for oneself, arrived at through one’s life experiences in connection to/with others over time. These connections are identity-forming, and this identity is the basis of the “self” that the very definition of autonomy (e.g. auto-nomos as “self-law”) references. Furthermore, the self that is created and maintained through such ties to others also plays an integral role in creating and maintaining the community or social context in

which it belongs. Therefore, the self finds itself in a reciprocal relationship with others, and this relationship is the interactive platform upon which autonomy operates.

In this chapter, I have discussed the relational approach to autonomy, emphasizing some of the important ways this approach diverges from traditional accounts. I have also offered a cursory overview of the perspective on autonomy that I find most compelling, which I will continue to explore through the remainder of the project. In the next chapter, I will discuss how autonomy, reframed as a relational ideal, compares with the traditional conception as it is expressed through the other different modes I have previously identified. These modes speak to what autonomy looks like in practice, how it is developed and exercised, and what treatment autonomous people can expect from others and their society.

## CHAPTER 5: DESCRIPTIVE AUTONOMY

In Chapter 3, I explored the essential features of an ideal in order to investigate whether and how the concept of personal autonomy fits this mode and what a commitment to such an ideal might look like. In this and the following chapter, I will discuss the other modes of personal autonomy that have been influential on popular culture, public policy, and the conduct of medicine, examining them through the lens of autonomy reframed as a relational ideal. Accounting for these different aspects is critical to understanding the benefits and shortfalls of how the concept of autonomy is currently employed in mainstream medicine and bioethics and how it might be transformed to better meet the needs of patients.

I will begin by using Brownlee's four components of ideals (comprehensiveness, aspirationality, constitutive cultivation, and unrealizability) as a starting point for the examination of the other operational mode that completes half of Anderson's equation (e.g. "what gets you autonomy"): the descriptive mode. The "ideal of autonomy" and "descriptive autonomy" are closely related, and on many accounts, coextensive. That is to say that accounts of the ideal of autonomy are, to a large extent, descriptive, while

accounts of descriptive autonomy are often given in idealized terms. But, as previously discussed, while autonomy as an ideal provides the model toward which individuals may strive, this way of framing the concept does raise concerns about practicality and exclusion. As Christman asserts, “Autonomy as an ideal... may well be enjoyed by very few if any individuals, for it functions as a goal to be attained rather than a condition assumed for most people” (“Autonomy in Moral”). In particular, because ideals are aspirational and (at least temporarily) unattainable, these features make it difficult to identify a point or stage at which a person may (ever) be considered autonomous—whether functionally or maximally. Thus, the mode of descriptive autonomy addresses what striving towards the ideal might look like in practical terms and how to tell when someone is or is not making constitutive progress. But, while this mode speaks to the conditions for developing and exercising autonomy competency en route to full recognition, the issue of how individuals should be treated when they are not autonomous, or while their autonomy is still “in process,” as well as what they are owed once they have achieved a recognizable level of autonomy remain a significant ethical questions.

I will then shift the discussion towards the two modes that complete the other half of Anderson’s formula (i.e. “what autonomy gets you”): normative autonomy and autonomy as a right. These modes speak to what individuals can expect from others or society in terms of the benefits, privileges, responsibilities and limitations of being

recognized as autonomous agents. These modes also invite serious consideration of how to judge individuals' capabilities, obligations, and liberties when their status as autonomous agents is unclear (for example, in the case of children, people who are developmentally disabled, or those with advanced dementia).

### **Cultivation of Autonomy**

By reframing the ideal of personal autonomy in relational terms, proponents of this approach have sought to address some of the major shortcomings of the traditional view, including interpretations that it is exclusionary, promotes undesirable qualities, or is not genuinely valuable. While relational accounts have reaffirmed the value of personal autonomy, certain qualities of the ideal do continue to pose challenges. Recall from Chapter 3 that Brownlee's "unrealizability" condition requires that ideals are, at least temporarily, unachievable. This may be true for various reasons, including that the requirements of cultivation are unsustainable, or the ideal is literally impossible to achieve given current realities, or because there is no defined goal or set point that marks maximum achievement or perfection. Those who espouse the ideal of personal autonomy generally hold that the demands of its cultivation are, in fact, sustainable, and that the ideal speaks to a condition that is humanly achievable. Where unrealizability elements enter the picture, then, is with regard to the latter circumstance, whereby personal autonomy is understood as an "ongoing progress ideal."

The mode of descriptive autonomy emphasizes the conditions that need to be met in order for a person to be considered autonomous. But, if the ideal permits continuous development or improvement, then personal autonomy becomes a moving target, which can make it difficult to identify a point or stage at which a person may (ever) be considered autonomous. However, if the idea is to be of any practical use (that is, if we wish to assert that someone can actually *be* autonomous, rather than just aspire to it), then there must be a way of recognizing those who have come close enough to qualify, even if no one has yet achieved perfection in this regard. This consideration opens the possibility of gradual or stepwise progress towards this goal, where a person is considered autonomous upon reaching a certain threshold.<sup>15</sup>

The idea of a threshold level, or of developing autonomy in stages or by degrees, is compelling from a relational perspective because it emphasizes the influence of relationships of care in nurturing burgeoning autonomy. This is because personal development (in general) is already strongly associated with connections to others (e.g. teachers, mentors, coaches, parents, etc.). In many cases, an individual's progress toward some goal is furthered or expedited through the influence of others who may offer support, constructive feedback, and access to the opportunities and infrastructure

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<sup>15</sup> The idea is prevalent in the literature. There are many variations of this idea, some of which can be found in the work of Marilyn Friedman, Ros Hague, Hugh LaFollette, Catriona Mackenzie & Natalie Stoljar, Diana Meyers, Onora O'Neill, and Susan Sherwin.

that enable growth. By contrast, without such connections, this development may be considerably more difficult, and in some cases, impossible.

This idea of gradual development is also related to the premise that autonomy is what Charles Taylor has called an “exercise” concept.<sup>16</sup> That is to say, one does not simply “have” autonomy as long as no one interferes, as if it is a static possession that one can store away or forget about. If someone “has” autonomy, but never utilizes it (e.g. they never act autonomously), it becomes doubtful whether such terms can appropriately be used to describe them. Similarly, autonomy is not something that is legally bestowed on someone when she attains the age of majority, like the right to vote or the liberty to legally drink alcohol. Instead, it is part of an ongoing process whereby people develop and hone certain skills and competencies that allow them to achieve greater degrees of autonomy.<sup>17</sup> In this sense, developing and maintaining (even a minimum level of) personal autonomy requires regular practice. In the same way as there is no meaningful sense in which we can say that a person is a “runner” unless she engages routinely in the practice of running, there is no meaningful sense in which we can say that someone is “autonomous” unless she routinely engages in the practices of autonomy. But in the same way that one is not born, but rather becomes a runner,

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<sup>16</sup> The distinction between “exercise” concepts and “opportunity” concepts comes from Charles Taylor. The application of this distinction to autonomy has been proposed by several theorists, including Robert Young (1986) and Natalie Stoljar (2011).

<sup>17</sup> The idea of “autonomy competencies” is commonly employed in the autonomy literature. The account that I am most indebted to in my own thinking comes from Diana Meyers, *Self, Society, and Personal Choice* (1989).

people also become autonomous in stages or by degrees, as part of a gradual process. As with a novice athlete who has just begun running, proper training and appropriate expectations are necessary to ensure success. If running a marathon is the athlete's eventual goal, at different times she may need to be either challenged (to develop endurance) or restrained (to prevent injury or fatigue), as well as given a range of developmentally suitable chances to test her progress.

Similarly, for the development of autonomy, especially in children, persons must be given the opportunities and space to develop and strengthen the skills pertinent to autonomy, but in a way that is tailored to not only their expected potential, but also their current capacity. Typically, this is a linear trajectory, with most persons demonstrating increasing levels of autonomy over time. But there may also be cases where individuals are, for whatever reason, simply not capable of meeting the requirements of autonomy at any time, just as some people will never be runners. Likewise, just as a proficient runner may suffer an injury, lose proficiency in her sport, or stop running altogether, there may also be circumstances that can cause autonomy to be diminished or lost. In liminal cases—such as an adult whose autonomy is called into question as a result of a medical crisis, or a child who is somewhere on the continuum but falls short of full descriptive autonomy—there may be significantly more difficulty in determining what these individuals are owed (socially, morally, or under the law) and what may be expected of them with respect to their status as autonomous agents.



Such liminal cases—especially involving children who may be on their way toward autonomy but have not yet “arrived”—demonstrate a paradox within the ideal. If autonomy is slowly, constitutively cultivated then the amount of time that nearly every person will spend below the accepted threshold (typically all of childhood, and perhaps beyond) is not negligible. During that time, it is not appropriate to hold such persons to the standards associated with full autonomy competency because they have not yet reached that stage of development; however, treating them as if they are not (yet) autonomous may also seriously hamper their ability to develop and practice the skills and attitudes that are necessary for them to actually become autonomous. Hence, Hugh LaFollette argues that, ideally starting in childhood, persons must have the time, space, and support necessary to practice—and become increasingly proficient in—the competencies that are part of autonomy before they are actually expected to achieve that threshold level. This includes being taken seriously by others as (potentially) autonomous agents, even at a time when this is not yet the case. Without these ongoing opportunities, LaFollette argues that children’s capacity for full future autonomy may be seriously jeopardized.

The imagery of the parent-child relationship is often invoked as a prime example of what relational autonomy means. In this analogy, a child enters the world fully dependent and with very little agency, and it is only through her relationship with others (primarily her caregivers), that she slowly, with encouragement, develops the

skills necessary to engage autonomously with the world—although she likely experiences hang-ups and hiccups along the way. But the achievement of some threshold level of autonomy does not require the child to eventually sever all ties with those who reared her and strike out on her own to prove her independence and self-sufficiency (although some people do choose to do this). Rather, from my perspective, the achievement of a threshold level of autonomy is dependent on an individual developing a certain degree of sophistication in her understanding of how her connections to others impact her own sense of self and her place in the community or wider world. Since a person's identity is relational in fundamental ways, and this identity undergirds personal autonomy, then an autonomous person is one who has developed a critical appreciation for what relationships are worth maintaining, what commitments she endorses because she is a relational being, how and when to prioritize those commitments above other particular preferences she may have, and what impact her actions have on herself and others.

Thus, the development of children from non-autonomous neonates to autonomous adults requires a certain type of time-released, controlled freedom. LaFollette calls this "circumscribed autonomy." The goal is not simply to familiarize children with the experience of making choices by giving them more frequent and weightier opportunities to exercise their skills. Equally importantly (if not more-so), children need to become accustomed to taking responsibility for their actions and living

with the consequences that their actions produce. Hence, as part of a deliberate and guided process, children gradually take on the full mantle of autonomy in a developmentally appropriate way.<sup>18</sup>

I would argue that this idea of “taking responsibility” is an essential competency of autonomy that is strongly related to the notions of accountability (as discussed in Chapter 4) and self-control or self-discipline. In this vein, I agree to an extent with Ros Hague’s claim that, “self-control is key to autonomy. If we cannot control ourselves, either we depend on others or we become slaves to nature” (157). Self-control, if understood in the sense of the ability to exercise self-restraint against one’s own impulses, is critical to autonomy because it is reflective of a certain type of relationship that one has to oneself. It is a way for an individual to permit herself a little time to take inventory of a situation and consider her options. It is a way to pause an action or a reaction in order to evaluate whether it is appropriate, justified, or conducive to one’s values, goals, and commitments. Self-control provides the opportunity for reflection

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<sup>18</sup> However, as useful as this imagery is, Barclay warns us not to be misled by the parent-child metaphor, writing, “We cannot presuppose that we each acquire autonomy competency as a natural consequence of maturation” (56). People can become less autonomous, or they can fail to develop particular autonomy competencies because of the influence of socialization, oppression, or other limiting factors. That children blossom into autonomous adults under the care, direction, and stewardship of their caregiver(s) is, of course, a best-case scenario. There are a variety of ways that this process can fail. Children may lack appropriate guidance or supervision, or they may face circumstances of serious deprivation, instability, or insecurity. They may face setbacks in their development or may be forced to take on more responsibilities or live with more consequences than is appropriate for their level of maturity and competency. Other factors, such as poverty, prejudice, violence, exploitation, lack of meaningful life opportunities, and other forms of oppression may also seriously undermine the development or exercise of autonomy on the part of both children and their caregivers. As I will discuss further in the next chapter, in the United States, attempts to protect individuals from some of the circumstances or influences that may thwart autonomy are embedded in law in the form of rights.

that often yields a clearer perspective that helps to minimize regret. This is important because, as Meyers argues,

[R]ecurrent regrets signal failed autonomy. Autonomous people take occasional regrets as opportunities to learn and to adjust their conduct and their plans. But when people are chronically regretful – whether because ongoing circumstances are hostile to their plans or because they repeatedly act in a self-defeating manner – their regret evidences their inability to control their own lives. Non-autonomous people are unable to use regret constructively. (35)

Self-control is a form of discipline that one imposes on oneself. This is an important aspect of autonomy that is often neglected. Autonomy is not simply freedom to (try to) do as one pleases as is often implied by popular representations of the idea. Autonomy requires a person to have the maturity to understand the necessity of rules and limits. Autonomy is as much about “self-discipline” (i.e. being subject to rules) as it is about “self-rule” (i.e. being the rule giver). These rules provide the structure that is necessary in order to set expectations, manage obligations and responsibilities, and realistically predict the likelihood of future events—all of which are essential components of feeling “in control” of one’s life.

If we have self-control, we are in a much better position to give an account of ourselves to others in the manner endorsed by Westlund (as discussed in Chapter 4). This is because self-control and self-discipline help to ensure that we are acting with

intention. The colloquial way of putting this is that we do things “on purpose,” where purpose implies reason and deliberate action, as guided by a self that, at least on some level, knows (and wants to do) what she is doing. This is essential to taking responsibility for oneself and one’s effects in the world. The centrality of these qualities to the development of autonomous persons can be seen, for instance, in the way that children (and adults) are often called upon in the event of the discovery of some wrongdoing to give an account of their conduct. This process provides a key opportunity for the development and practice of these autonomy competencies. In order to acknowledge responsibility for some wrong or harm and develop the appropriate response to it (e.g. employing empathy to understand how others are affected by our actions, and how we, in turn, are affected by their pain or embarrassment, and being motivated by this to make amends), children must understand and accept these consequences as causally related to the action they themselves originated.

Being unable to accept the consequences of one’s own actions signals a failure in an agent’s ability to see herself and her actions as intentional and relevant to the broader circumstances and general direction of her life. As such, self-control is an essential competency of autonomous individuals, and one whose development is best initiated from very early in life. Developing self-control requires practice and carefully curated opportunities to exercise choice in matters of increasing consequence (e.g.

where the desirability or undesirability of the consequences are carefully calibrated by caregivers to be developmentally appropriate teaching tools). Accounting for ourselves to others also establishes us as individuals by imparting knowledge to others of how we see ourselves. This, in turn, can help them to help us protect or restore our identity (and autonomy) during times when its integrity is threatened or in flux, such as when we experience serious illness or suffering.

Traditional emphasis on the “decision-making” aspect of autonomy (such as the weight attributed to the act of choosing between available options or possible actions, especially in healthcare) often obscures the fact that making a choice is itself an act of setting parameters. That is, when facing the choice of either “A” or “B,” the decision to choose “A” necessarily casts “B” aside, putting it outside the realm of availability. Thus, before one chooses, one is more “free,” at least in the sense that when both “A” and “B” were available, there were twice as many possible options or related outcomes. This is simply to say that the act of choosing affects the trajectory of one’s future. Sometimes persons choose wisely, and their choices permit them the greatest possible range of desirable outcomes. Other times, persons choose poorly, eliminating the possibility of some desirable outcomes and causing them regret. Being able to live with the outcomes of one’s decisions and the limitations that may result from one’s choices is crucial part of autonomy, whereas the opposite (inability to predict or cope with the outcomes of one’s decisions) is a sign that a key autonomy competency is lacking. This is also why,

as I will discuss, a more relational approach to autonomy in healthcare decision-making, is required. Although informed consent rituals are likely to continue indefinitely (at least out of legal necessity), enriching the context of patient decision-making by affirming the value of one's connections to others and the essential role they play in identity can help to alleviate some of the pressure on patients to choose independently—and wisely—especially when they are under the duress of pain or illness.

### **Authenticity and Temporality**

Because personal autonomy is constitutively cultivated, being autonomous is an unceasing endeavor. There is no meaningful way to understand someone as “statically” autonomous. One may reach a point at which we can say that she is descriptively autonomous—that is, she has met the relevant criteria for such recognition—even though it is likely that there is no saturation point at which she will finally and indisputably achieve the ideal of being maximally autonomous. But in the same way that physical fitness requires ongoing effort to maintain it, because the exercise of autonomy is constitutive of the ideal, if one were to finally climax at a point of maximum autonomy and cease to exercise the required competencies any further, she would, on most accounts, diminish her autonomy considerably.

While it is not a perfect metaphor, it may be helpful to think of personal autonomy like sailing a large ship, where the individual is the captain (where such a

title implies achievement of at least baseline experience and proficiency correlative to this role) and her connections to others are the crew. The wind, water, atmospheric conditions, and other vessels on the water are the external social factors that are an integral part of the experience and outcome of the enterprise. In this example, the captain has in mind certain objectives for the voyage (e.g. reaching some port in  $x$  amount of time) and she works with her crew to navigate through whatever conditions present themselves during the journey. The entire experience may be one of smooth sailing, where the external conditions are entirely conducive to the captain's plan and the journey presents few obstacles or challenges. During these times, very little intervention or adjustment may be required, although she will need to remain attentive to ensure that she is staying the course and that everything is going to plan. But such smooth sailing is by no means guaranteed; therefore, in order for her to be the captain, there must also be a degree of confidence in her ability to competently meet challenges when they arise, and she is, in fact, somewhat accountable to her crew in this regard.

Autonomy in this example is relational in two ways. First, the external environmental conditions are constitutive of the experience of sailing. That is to say, for instance, that the water is not just a factor that influences the vessel or its speed and trajectory. It is an essential part of what it means to sail. If there is no water, it is simply not sailing. Second, the individual requires the crew's attention, support, and cooperation in order to successfully sail the boat. She may choose the destination and



take responsibility for navigation, but she depends, in important ways, on her relationship with the crew (and the cooperation of the external environment to some extent) to actually carry out these intentions. In this relationship, there are agreements and commitments between captain and crew that are essential to the venture. She is accountable to them to fulfill her part, and she likewise depends on them to fulfill theirs. But if her crew is lacking in some way (inattentive, absent, not proficient in the necessary skills, etc.) then she may attempt to fulfill their roles in addition to her own (e.g. adjusting the sails, redistributing weight, taking in and letting out line). However, in such a situation, there is a greater risk that she may be unsuccessful in maintaining control over the ship when there are fewer others upon whom she can depend. If external conditions are especially difficult (e.g. heavy winds, large swells, driving rain), it may be impossible for her to maintain control over the vessel. She may be overwhelmed or exhausted or incapacitated by anxiety or inexperience. She may simply not have the resources or the competence to be assertively proactive (or even effectively reactive) in such circumstances, even if she may theoretically know what needs to be done.

But there is another element that is also important in this metaphor that has not yet been explicitly discussed, and that is temporality. Since personal autonomy is an ongoing exercise, its strength or expression may ebb and flow in response to changing relationships and circumstances over the course of one's life. As a result, the captain's

proficiency in sailing a vessel cannot be accurately determined by closely examining any one particular time point of the journey, or even any one particular journey (especially if her sailing career is long). There is a need to look at the development and exercise of personal autonomy in the context of one's life, which includes not only the present moment, but also one's past and one's expected future.

This temporal aspect of autonomy is also strongly correlated with identity and authenticity. Autonomy is a type of relation that one has to oneself whereby an individual consults with herself to ascertain whether she is (or is becoming) who she really wants to be. Hence, a primary component of this relationship is personal identity, which is developed in part through one's connections to/with others, and in part through one's ability to exercise (some level of) creativity and control in refining one's picture of oneself. Thus identity, like personal autonomy itself, is constitutively cultivated—where cultivation implies a process of discovering, creating, and remodeling oneself over time, in ways that are shaped by and responsive to one's connections and external environment. In feminist theory, this process of identity-formation that is responsive to both internal and external conditions is sometimes represented by the concept of “intersectionality.”<sup>19</sup> Intersectionality speaks to the way that identities are formed at the crux of a variety of converging sources of power, privilege, and oppression. It involves recognition of the fact that an individual may not

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<sup>19</sup> Intersectionality is a well-known theme in feminist theory, and is advocated by many theorists including Patricia Hill Collins, Kimberlé Crenshaw, and Maria Lugones (among others).

have one singular, cohesive identity; rather, she may be pulled in many directions at once, or different identities may come to the fore (or fade into the background) in different social circumstances. In this way, identities can be said to have a social location or “place,” while the process through which such identities are negotiated introduces the element of “time.”

In order to be autonomous, an individual must have (among other things) some level of coherence between her understanding of herself, her actions and choices, their outcomes, and the general direction of her life. In many accounts of personal autonomy, this coherence is portrayed as “authenticity.” Calling to mind the distinction discussed in Chapter 3 between procedural and substantive accounts, there is one concern for the procedural approach that I had not previously discussed, which bears on this issue—namely, that with a limited emphasis on the criteria or process of rational decision-making, such accounts may fail to secure the authenticity that is required for a robust and meaningful conception of autonomy.

Most conceptions of personal autonomy specify some requirement of authenticity of desires or motivations, with the implication that merely being able to act freely on the basis of desires or values does not guarantee autonomy. Rather, to be autonomous, there must also be some sense in which an individual identifies with those desires or values that are motivating her, not out of coercion or blind deference, but because they resonate on a deeper level with “who she really is.” This is the quality that

Mill referred to as character. For example, in Meyers' account, personal autonomy requires a degree of self-awareness and self-reflection such that, "one must know what one is like, one must be able to establish one's own standards and to modify one's qualities to meet them, and one must express one's personality in action" (20).

In hierarchical procedural accounts such as those proposed by Harry Frankfurt or Gerald Dworkin, this is usually specified by the condition that an individual's higher-order desire supports a lower-order one (i.e. it is one that she would reflectively endorse, or at least that she would not repudiate or be alienated from).<sup>20</sup> For example, an individual who is driven by a more basic desire (e.g. to indulge in eating sweets) acts autonomously if this volition is ratified by a higher-ranking desire (e.g. to take advantages of the small pleasures in life and not deny herself this enjoyment), but acts heteronomously if her higher preference conflicts with or leads her to disavow the lower one (e.g. she prefers to deny herself these indulgences in order to obtain another goal, such as weight loss). With regard to hierarchical procedural accounts of this sort, questions have commonly been raised concerning how to determine whether a higher order desire is authentic without infinite regress (e.g. that each preference must be endorsed by the one that ranks higher than it, *ad infinitum*) and how to account for the

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<sup>20</sup> This language of reflective endorsement and (non)alienation regarding desires or volitions is common in the literature. I am not aware of a proper singular citation for these terms, although I know they are often utilized by John Christman. Discussions of hierarchical accounts of procedural autonomy (in general) are also quite ubiquitous. For other theorists who utilize this language, see: Christman, Dryden, Dworkin, Frankfurt, Friedman, Mackenzie and Stoljar, Piper, and J. Taylor.

possible effects of coercion, manipulation, or other external controls on preference formation (e.g. a person's lower-order desire is endorsed by her higher-order desire, but the whole process has been compromised by the coercive effects of oppression or some other force).<sup>21</sup>

One possible solution for conundrums of this sort that I find compelling is to emphasize the importance of an individual's personal history in determinations of authenticity and autonomy. This approach recognizes that knowing what one is really like and being able to reconcile one's sometimes disparate or conflicting drives, experiences, relationships, and identities into an integrated, authentic self entails a significant temporal commitment. It builds on the understanding that a reliable sense of self develops slowly over time through a dynamic process that includes the accumulation of life experiences. This process requires not just that things *happen to* a person, but also that she make a conscientious effort to make sense of her experiences, connections, and acquired values or desires so that she can begin to shape her life in ways that feel true to her. In this sense, the self is what Christman calls a "socio-historical" entity. It is durable and maintains a certain integrity over time, even while also being constantly "in progress."

A problem with many characterizations of autonomy, Christman argues, is that they look at it from a "time-slice" perspective (*Politics* 137), which examines certain

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<sup>21</sup> Both of these questions have been discussed by J. Taylor, but also appear in works by many other authors.

events or decisions in isolation and asks whether the individual or the decision was, at that moment, autonomous. As a result, a person may, in a particular instance, satisfy minimum criteria (e.g. competence, procedural independence, reflective endorsement, etc.), but still fail to be autonomous when that instance is examined diachronically. The example frequently used to illustrate this point is that of a very effective hypnotist who radically changes an individual's higher-order desire without her knowledge.<sup>22</sup> In that case, the hypnotized person may experience no conflict between her higher and lower order desires, and she may even reflectively endorse any actions she takes in accordance with those desires. But the question of authenticity arises because the origin of those desires is an imposition by an external force (over which she had neither knowledge nor control). From a time-slice perspective, this discrepancy would not necessarily be revealed. But, Christman argues, "Given that a person is embedded in, if not constituted by, the flow of events that form her life, autonomy must be seen in relation to that flow rather than as independent of it" (*Politics* 137).

Christman is not the only one to argue for the significance of an individual's personal socio-historical context. The distinction that is sometimes made between "local" and "global" autonomy is meant to capture the difference between looking at autonomy from such a "time-slice perspective" (e.g. asking whether a person is autonomous in a particular instance, or relative to a certain decision or drive) and

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<sup>22</sup> The hypnotist example, or some variation thereof, is utilized in many works on a variety of topics (free will, compatibilism, autonomy, etc.), including work by Mele, J. Taylor, etc.

looking at it from a holistic perspective (e.g. whether a person is descriptively autonomous in a fuller, enduring sense). Meyers makes a similar distinction between “episodic autonomy” (e.g. instances of autonomous decision-making) and “programmatically autonomy” (e.g. autonomous living). On Meyers’ account, the development of programmatic autonomy is punctuated by the achievement (and maintenance) of certain threshold levels, as exemplified by increasing proficiency in the autonomy competencies she identifies—competencies which both enable and require some “episodic” or spontaneously autonomous activity, even if a person is not (yet) fully descriptively autonomous.

In Meyers’ account, it is both through and as a result of this development that individuals are able to design, revise, and carry out their own authentic life plans. Meyers defines a life plan as “a largely schematic, partially articulated vision of a worthwhile life that is suitable for a particular individual” (Meyers 51). Having a life plan of one’s own design is the mark of programmatic (or global) autonomy and the safeguard of episodic (local) autonomy and spontaneous conduct. Because autonomous life plans are durable, yet are responsive to changes in one’s desires, self-concept, or circumstances over time, they provide a useful rubric for evaluating the direction and events of one’s life as they unfold. While for Christman, an important part of autonomy is how the present (including one’s present sense of self) is shaped by the past, for Meyers, more emphasis is placed on how one’s sense of self and degree of autonomous

development shapes one's present and future possibilities. In either case, ascertaining whether one is autonomous requires looking at a fuller, temporally situated picture of the individual. This approach stands in contrast to the more myopic focus on the criteria of rational decision-making that is common in many procedural accounts.

In a related vein, Baumann also argues for a diachronic approach to personal autonomy, but he criticizes accounts like Christman's, which he argues still reify certain moments of decision-making, stringing them together as a historical collection of evidential episodes to use in determining whether a person is autonomous. This "additive" approach, he argues, offers a moderately representative sampling of a person's actions over time, but it still does not get at the heart of what autonomy is. Baumann writes, "By contrast, the suggestion that autonomy is a property of a person's way of living, which I want to make plausible, is the view that whether a person is autonomous cannot—for conceptual and not for epistemic reasons—be determined by looking at single points of time" (459).

Building on Baumann's arguments about the diachronic nature of autonomy, I would agree that personal autonomy is not a discrete property of a person or action as examined at any particular moment (or string of moments). Such a static or "time-slice" view of autonomy cannot be used to adequately ascertain whether a person is autonomous. Rather, personal autonomy is a relationship to oneself over time. It is an emergent property of a whole life viewed appropriately in the context of (social) place



and time. As Baumann explains, personal autonomy is like “relations of trust or of friendship. It is impossible to adequately describe a property of trust or friendship that applies to single points of time... One must rather understand these relations in a diachronic way” (466).

Later in this project, I will use this relational, temporal approach to critique the traditional focus on episodic autonomy in healthcare and medical research settings. I will show that this staccato approach to patient autonomy—which often culminates in the ritual of informed consent<sup>23</sup>—is inadequate because it isolates particular instances of “punctate decision-making” (Kukla) to utilize them in exactly the way that Baumann criticizes—as the relevant data points for proving that a patient is/was autonomous. As a result of this limited focus, patient autonomy is often not evaluated in the appropriate context. This reductive approach minimizes the importance of understanding patient autonomy in the context of a whole life—which includes the patient’s sense of self (a self whose integrity may be threatened by the experience of pain or illness), her connections to others, and her own understanding about her place in the world and her life’s trajectory.

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<sup>23</sup> References to the “ritual of informed consent” are common in bioethics literature and I am unaware of who originally coined this phrase. Two scholars who have used this phrase that immediately come to mind are Onora O’Neill and Rebecca Kukla, although there are doubtless many others.

**CHAPTER 6:**  
**NORMATIVE AUTONOMY AND AUTONOMY AS A RIGHT**

The prescriptive or normative approach to autonomy invites us to think about how best to respect someone's autonomy, what limits can or should be put on a person's autonomous action, and how to treat someone who is not autonomous or whose status as an autonomous agent is unclear. But to deduce what someone is owed and how she ought to be treated with respect to her autonomy (or degree of lack thereof) is a complicated matter, and it typically has a strong correlation with one's moral commitments, the legal and cultural norms of one's society, and the criteria for autonomy (either ideally or descriptively) that are also being endorsed. For those who are unambiguously autonomous (by whatever the relevant measure may be for a particular society), it is generally easier to deduce what kind of normative obligations and privileges this status entails within a given cultural context. But for those whose status as autonomous agents is indeterminate, the inability of others to clearly ascertain their competencies may lead to disparate treatment from others and under the law.

In this chapter, I will discuss the ways in which the ideal of autonomy (as a model) and descriptive autonomy (as the conditions of development and exercise) have

been interpreted, through the use of rights language, to set the legal parameters for the treatment of autonomous individuals. However, the operational mode of “autonomy as a right” brings a considerably different tone to the discussion—namely, that it is when autonomy is framed as a right that it is most likely to be expressed in the traditional, individualist terms that have been criticized in this project. But it is perhaps for pragmatic reasons that this is so: when it comes to enumerating the obligations of government to citizens and the protections of citizens under the law, simplicity is key. Setting defensible expectations for individual liberty is easier when there are fewer contextual (relational) elements and moving parts to consider. But the relational approach to autonomy is messy. Connections to/with others are complex and boundaries are not easily delineated. The sheer volume and diversity of social and political considerations that may come into play in any particular case complicate things even further. Thus, for the sake of clarity, consistency, and ease of government, minimum requirements and expectations have been established. However, in the effort to make protections of personal autonomy enforceable, the concept has been pared down to more manageable form, unfortunately with a loss of appreciation for a certain amount of the concept’s intricacy.

Thus while age or competence are often conditions for granting certain legal entitlements associated with autonomy under the law, these criteria alone cannot guarantee that a person is actually autonomous. Nonetheless, in the absence of strong

evidence that a person does *not* meet at least the minimum accepted standards for autonomy within a society, I would argue that she should still be treated *as if* she is autonomous without prejudice under the jurisdiction of legal and institutional policies. This intuition is based on a distinction made by Sonya Charles between “psychological autonomy” (or what I have called here personal, descriptive autonomy), which she believes requires a strong substantive approach, and “autonomy as a right,” which she associates with justice and a procedural approach. Charles argues that in the absence of widespread agreement about the ideal of autonomy and its defining characteristics in development and practice, this distinction permits philosophers to “remain agnostic about what personal autonomy actually requires” (since no singular account has yet settled the debate) while also challenging “oppressive norms that restrict [person’s] freedom and control over their lives” (Charles 428).

This approach can be used to recognize that autonomy is an “ongoing progress ideal,” developed and maintained in stages or by degrees, and that as such, some people may be more experienced or skilled than others in the competencies of autonomy. Yet by setting eligibility for the protection of these rights at the minimum, all persons at (or above) a certain threshold of autonomy may nonetheless expect the same treatment by others and under the law. This distinction also useful in highlighting where the work needs to be done to reform the way the concept of autonomy is translated into “patient autonomy” in medical care and research. By expanding the

operational understanding of the ideal of autonomy in relational terms, bioethicists can help to relieve some of the pressure that is put on patients and providers with regard to medical decision-making by broadening the scope of what providers and institutions may recognize as an “autonomous” choice while still offering minimum legal protections in the form of informed consent.

### **Autonomy as a Right**

As discussed in Chapter 2, in the liberal tradition, autonomy and rights are intimately related. In the United States, it is common to frame the understanding of what treatment or protections persons are owed in terms rights, and this is part of what has given the concept of autonomy its particularly individualistic flavor. In many liberal accounts, an autonomous individual is one who is free to pursue his own life projects without interference from other actors or entities, and rights are what protect individuals from encroachment and offer them redress should intrusions occur. Although a distinction has been made between the idea of “normative autonomy” and a “right of autonomy,” one typically invokes the latter *because* it has normative implications. For example, an appeal to the right of autonomy may be made in order to emphasize or justify an individual’s authority over herself. If one has a “right of autonomy,” the implication is that she has a certain freedom to manage her own affairs that ought to be respected. She may entreat others not to impinge on her autonomy by, for example, making choices on her behalf that she is competent to make and would

prefer to make for herself. Or she may insist that another party lacks the power to override her claim to autonomy by asserting immunity to the interference entailed by compulsory child vaccination laws. By framing autonomy as a right, this conception draws strength from its relationship with political theory, where appeals to rights of this sort are often validated either through formal instantiation in public policy and the law, or through favorable judicial interpretations that set the precedent for future protections.

George Rainbolt asserts that rights are created by a rule system and are relative to it; as such, to articulate the normative force of an appeal to the “right of autonomy,” it is useful to know whether it is being identified as a legal right, a moral right, or both. As previously discussed, in the United States, the popularly asserted “right of autonomy” is not legally enumerated even though it is, arguably, one of the most recognizable and deeply treasured principles of American citizenship. One explanation for this posits that this is because autonomy is foremost a moral right, and moral rights exist “prior to and independent of... enactment by legislatures” (Feinberg 197).<sup>24</sup> That is to say that it is the sort of right that transcends the bounds of any particular government’s explicit recognition of it (or lack thereof). But since legal rights (as

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<sup>24</sup> To clarify, as I have discussed it, “moral autonomy” is a particular species of autonomy concerned with morality, conscience, and concerns of that nature. A “moral right of autonomy” (or autonomy as a moral right) draws on the concept of moral rights which, according to Thomas Pogge, are rights based on particularly weighty moral concerns that are broadly sharable and which trump most other concerns (54). There are a variety of accounts that posit autonomy as a moral right. One example is Edmund Pellegrino’s, “Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship” (1994).

opposed to moral rights) are codified and enforced by the governments or institutions that recognize them, their existence (if not their scope and legitimacy) is not frequently disputed. So it is often easier to determine the status of a legal right (e.g. whether it is protected in practice, whether it has been overridden or infringed upon, etc.), and there is usually some recourse available for individuals or groups who feel that their rights have been violated. But when moral rights are not also represented as legal rights, it may be more difficult to secure recognition for them since they may not be universally respected, and there may be no legal basis for enforcement or reparation in the event of a transgression.

One way that the right of autonomy has gained some legal protection in the U.S. is through the interpretation that it *is* a legal right, but one that is implied by the amendments to the Constitution and the spirit of the document as a whole. This argument posits that legal rights protect citizens' autonomy since they are designed to grant liberties and immunities that protect freedom, and freedom and autonomy run in tandem. By this reasoning, the Constitution and the body of the law protect a general right of autonomy by expressly addressing the constitutive elements of the concept that have been recognized as most essential and most liable to infringement. A similar argument has been made for the right of privacy, which has also been correlated with personal autonomy in the traditional view of the ideal. Doug Linder demonstrates this line of reasoning by reframing key clauses from the Bill of Rights in terms of their

privacy implications: privacy of beliefs (1<sup>st</sup>), privacy of the home (3<sup>rd</sup>), privacy of person and possessions (4<sup>th</sup>), privacy of personal information (5<sup>th</sup>), along with a provision for the possibility of other non-enumerated rights (9<sup>th</sup>). In these amendments, the right of privacy entails privileges and immunities that protect some of the most fundamentally important and autonomy-affecting interests of persons. This has also been the interpretation used in the majority opinion of a number of Supreme Court rulings that have upheld individuals' autonomy in the areas of contraception, reproduction, childrearing, sexuality, marriage, and the refusal and termination of medical treatment.

In addition to the difference between legal rights that have been codified and those that exist primarily through implication or interpretation, there is also another important distinction to be made that bears on the way that personal autonomy is interpreted and recognized in popular perceptions and under the law. The distinction between "positive" and "negative" rights—where the former describes an entitlement to the provision of some benefit, while the latter describes a freedom from interference—points to an essential difference in how the ideal of autonomy is interpreted and recognized in the current dominant conception as compared with the relational approach.

In the typical view of autonomy, appeals to such a right typically come in the negative form, carrying with them the normative implication that individuals should be left alone to do (and live) as they please unless there significant and compelling reason



to intervene. Negative rights tend to receive greater emphasis in the American legal system because they resonate well with the traditional cultural emblem of the “rugged individual” whose self-sufficiency is a defining feature. Negative rights serve this ideal since they aim to liberate the individual from unwelcome constraints by others, making it possible for individuals to freely pursue their own stake in the American Dream. On the other hand, positive rights are often seen in contrast to this picture of independence, competition, and hard work (interpreted as the basis for “successful” citizenship) because they make claims upon others for the provision of some goods or services. Positive rights challenge the myth of self-sufficiency by recognizing some aspects of human dependence and affirming that some form of social or governmental support is necessary in order for an individual to meet all of her needs. This also requires a greater-than-baseline level of agreement and social cooperation for the protection and fulfillment of positive rights in a way that negative rights do not.

In the United States, the right of autonomy, construed as a negative right, draws force from its association with privacy and property rights. As Gaylin and Jennings argue,

Autonomy understood as negative liberty appeals to metaphors of space. It wants elbowroom—a place of one’s own... Negative liberty requires fences and boundaries for protection against outside intruders. It rests on a conflict-ridden

and antagonistic picture of social existence, in which each individual struggles with everyone else to control his own patch of ground. (41)

This imagery harkens back to the drafting of the U.S. Constitution, when the framers struggled with the issue of how to protect the interests of individuals against encroachment by the collective. Nedelsky has proposed that property became a focal point since it operated both as a metaphor for this tension, as well as a significant immediate concern. In this context, property, privacy, and autonomy became strongly linked. On or with one's own property, an individual could do as he pleased; within its boundaries, one could expect (or demand) privacy. Thus, individuals were seen as most fully autonomous in the seclusion of this space, secured by legal rights against the intrusions of others. In a similar vein, the body came to be seen as a special kind of property that retained the rights of privacy and noninterference even as it moved about in otherwise public space.

It is clear that from their origins, these notions were deeply affected by the gender, racial, and class biases of the times. Not all individuals were entitled to property ownership—either property in themselves (à la Locke) or in terms of tangible holdings. Women, slaves, and the poor were systematically excluded from owning property, and by extension lost the benefits of property and privacy as integral components of the dominant conception of autonomy. Under these restrictive social conditions, such individuals were seen as unqualified for full citizenship on the basis of

having very little to protect under the auspices of negatively-construed rights (e.g. not having the requisite physical or intellectual interests or holdings to warrant protection) and being ineligible (as non-citizens, or at least not “full” citizens) for the provision of the goods or services entailed by any recognized positive rights.

In a similar fashion, as I have previously discussed, some critics argue that the current incarnations of these ideas still bar some individuals or groups from being recognized as autonomous persons and from enjoying the full range of privileges associated with this recognition. For instance, Margaret Wardlaw argues that the continued emphasis on individualism and self-sufficiency that can be seen in popular culture, medicine, and the law, promotes a conception of autonomy that disenfranchises people with disabilities. She claims that a significant reason why the needs, concerns, and rights of disabled people are frequently overlooked or overridden in American law, bioethics, and healthcare practice is, in large part, attributable to the cultural preoccupation with the version of autonomy that can be expressed primarily in terms of negative rights. Seen as minimally intrusive measures for safeguarding the interests of autonomous agents, negative rights provide some measure of social control by implying that an individual has legal recourse against others who interfere unjustly with the pursuit of her life plans. From this perspective, the autonomous agent is framed as one who need only interact with others if she so chooses, and then only

within the parameters that she sets, while otherwise being protected from the actions, demands, or even presence of others.

By contrast, Wardlaw argues, “To be disabled in a way that requires—as disability often does—physical dependence on another is to be the opposite of the lone rights-bearer, the opposite of a freely functioning citizen, and in a significant and emotionally compelling way defines one as less than human” (54). She suggests that the rights most relevant to people with disabilities tend to be positive rights (rights that fundamentally entail relationship with some other, whether a person or another entity), or perhaps negative rights that “necessitate positive provisions” (48) in order to have the same meaning and effect for disabled persons. In the traditional framework, positive rights, which can be seen as emphasizing connectedness and dependence on other people, are undervalued compared with negative rights because they allude to the ways that individuals are not self-sufficient.

Because people with disabilities do not fit within the traditional American narrative, their social or legal concerns (especially as pertains to positive rights) rarely capture significant attention. When they do, it is often because the circumstances in question appear to mirror—rather than challenge—conventional social biases. As many disability theorists have noted, there is cultural tendency to characterize people with disabilities as passive “victims” of their conditions, with the attendant misconception that when disabled people experience significant limitations or suffering, it can be

primarily (or even solely) attributed to their bodies.<sup>25</sup> This assumption can even be seen in the way that contemporary medicine interprets concepts like health, disease, suffering, and quality of life in order to define the goals of care. These interpretations have the effect of both reflecting and projecting the assumption that, “the state of health is normal, natural, and that those who are not healthy have somehow failed to achieve this normalcy” (Bluhm, “Vulnerability” 157). In this way, disability is posed as an abnormal or unnatural condition that exists outside the accepted parameters of corporal variation, so much so that “disabled people are reminders of the failure of modern medicine” (Wardlaw 53). These misconceptions camouflage the degree to which disability is constructed and maintained (both accidentally and deliberately) by exclusionary, neglectful, or apathetic attitudes that undermine efforts to conscientiously redesign social policies, architectural design, and other facets of community life to be more representative. They also help to exculpate able-bodied people from social responsibility for the failure to recognize or challenge these cultural shortcomings.

However, there are some circumstances that do garner public attention and concern for the rights or autonomy of people with disabilities. Typically this concern comes in the form of moral support for a disabled person whose pursuit of the right to refuse life-sustaining medical treatment or the right to die is being thwarted by medical

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<sup>25</sup> Carol Gill, Sara Goering, and Susan Wendell, among others, have discussed topics related to this claim, such as disability in the context of the right to die movement, the inadequacy of quality of life assessments of disabled people in medicine, and the social construction of disability.

or legal authorities. This plight resonates with many individuals' understandings of the (negative) right of autonomy while also confirming their assumptions about the source of disabled people's suffering and their quality of life. It is also a good demonstration of the previously discussed feminist critique that the overvaluation of autonomy diminishes support for other social or moral goods. As Wardlaw persuasively argues,

By reconstituting the disabled person within the context of an individual struggle for negative rights, we transform her from the helpless sufferer who is *lebensunwertes leben* [life unworthy of life] into an autonomous advocate for her own rights. While institutionalized, the disabled person is a humiliated and dehumanized sufferer, but while she is a citizen fighting out a courtroom battle she fits well into the radically constricted notion of what it means to be human in the context of a highly individualistic society. (56)

This conflict demonstrates one of the significant shortcomings of the traditional, historically-informed, rights-based conception of the ideal of autonomy: namely, that the resulting emphasis on negative rights undermines recognition of the interdependence, vulnerability, and need for care that is experienced by all people at various points in their lives.

## **Segue**

In the last few chapters, I have explored the concept of personal autonomy as it operates across a variety of modes. To frame the discussion, I contrasted the traditional

view of the ideal with a newer, relational approach, arguing that the latter provides a more representative and fruitful way of understanding the concept that better aligns with what it means to be a socially-constituted person. I then showed how reframing the ideal in relational terms changes the expression of the concept in the other modes, especially highlighting the differences in perspective and applicability between the ideal of autonomy and descriptive autonomy, on one hand, and normative autonomy and autonomy as a right, on the other.

Having discussed what autonomy is, what challenges the traditional conception entails, and what I think is the most promising response to these challenges, I now move the discussion to how the autonomy has been translated into bioethics and contemporary medical practice. I argue that the traditional conception that has been adopted in this arena is problematic in the way that it focuses on individualism and choice, often reducing the complexities of protecting and promoting patient autonomy to the question of whether or not a patient has provided informed consent. In the next part of this project, I will compare the relational approach to autonomy with the conventional one, giving special attention to how the experience of suffering (as associated with pain, illness, or other malady) impacts autonomy through its effects on identity. I will then show how the relational approach can be fruitful for improving healthcare practices and changing patients' and providers' expectations for the clinical encounter in ways that may better relieve suffering and promote genuine autonomy.

## CHAPTER 7: PATIENT AUTONOMY

For more than forty years, patient autonomy has been a driving concern in Western medicine and research. Amongst the three principles of research ethics identified in the iconic 1979 *Belmont Report*, “respect for persons” has ascended to primacy, often interpreted as respect for *the autonomous choices of persons*.<sup>26</sup> Similarly, among the four concepts identified by Beauchamp and Childress that are now commonly taken as the foundational principles of bioethics (beneficence, non-maleficence, respect for autonomy, and justice), autonomy stands out as the most widely recognized and frequently discussed. However the conception of autonomy most commonly featured in these discussions is rarely relational in the ways described in this project. Instead, autonomy is typically portrayed in the traditional manner, with a strong accent on individualism and individual rights—although, given the events that led to this increased attention, it is not difficult to see how this particular expression of autonomy initially took hold in this arena.

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<sup>26</sup> The three principles of the *Belmont Report* are: respect for persons, beneficence, and justice.



Early global and federal research regulations such as the *Nuremberg Code* and the *National Research Act of 1974*, and indeed the discipline of bioethics itself, were all instituted in direct response to an increasing number of controversies in medical practice and human research that had begun to come to light in the mid-twentieth century.<sup>27</sup> The common thread amongst these abuses was the blatant disrespect and disregard for patients' and research participants' needs, preferences, wellbeing, and bodily integrity. As such, when these events were publicized, it made sense—especially within a culture already so accustomed to thinking in terms of rights, property, and privacy as the United States—to frame these violations as attacks on the individual's sovereign domain (her body and life) by others who exploited vulnerability, violated trust, and overstepped boundaries. Thus, the solution to these issues seemed clear: giving greater attention to patient autonomy by accentuating choice, voluntariness, and self-sovereignty, while deterring providers and investigators from ethical trespasses through policy changes that increased regulation, oversight, and accountability in research and clinical practice.

Despite widespread repudiation of publicized cases (e.g. Nazi medical experiments, Tuskegee Syphilis Study), the early emphasis on more stringent clinical and research oversight and the promotion of patient autonomy was met with

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<sup>27</sup> In addition to the well-publicized cases, Henry Beecher's exposé, "Ethics and Clinical Research" (1966) in the *New England Journal of Medicine* highlighted twenty-two cases of ethical misconduct in research in the United States. Beecher's article concluded that informed consent and investigator conscientiousness are the two most important safeguards against future violations.

considerable resistance. U.S. providers and researchers were indignant at having comparisons drawn between their work and the egregious wrongdoings of others that had made headlines. Many felt that the overwhelming majority of their work was already well aligned with the principle of beneficence. As such, they failed to find anything sinister in common medical practices such as shielding patients from too much information or difficult diagnoses, minimizing or overriding choice when it was determined to be in patients' best interests, or misleading some patients in the interest of conducting important research—especially research for the sake of the greater good. Yet owing to the hard work of bioethicists, healthcare providers, and lawyers over the last several decades, this resistance has been largely overcome. Respect for autonomy is now dogma in Western medical education and practice. In fact, the pendulum has swung so far in this new direction that the value and necessity of being vigilant about protecting patient autonomy is now typically taken as primary and self-evident.

This fervent emphasis on patient autonomy has inspired many changes in the areas of law, healthcare administration, medical pedagogy, and provider-patient relationships. One of these changes has been the effort to elevate the status of the patient, shifting away from traditional conceptions of the patient role which have typically been associated with passivity and suffering, toward patient “empowerment” or “self-efficacy,” which is now associated with increased patient autonomy. In practice, this shift is accomplished in part by distilling “autonomy” down to the more

manageable “autonomous choice.” This has several consequences that can affect nearly all aspects of clinical practice and research, sometimes in undesirable or unintended ways. This emphasis on choice recasts the medical encounter in terms of consumers and services, undervaluing the importance of the *relationship* between patients and providers. This shift permits the further reduction of “autonomous choice” to “informed consent,” which moves the accent away from the patient (as a person who is being asked to decide), instead homing in on the process and documentation of that decision. This substitution also reinforces a “time-slice” view of patient autonomy which, as discussed in Chapter 5, strips away much of the context of a person’s life to order to validate or invalidate particular moments of choice as “autonomous.” Furthermore, autonomy-as-informed-consent can mask realities of persistent vulnerability, uncertainty, and power inequality—all of which bear significantly on the provider-patient relationship, suffering, patient experience, and autonomy. In this chapter, I will explore each of these aspects.

### **Choice and Consumerism**

Perhaps for reasons of expediency, there is a tendency in bioethics and medical practice to focus on “autonomous decisions” rather than “autonomous people.”<sup>28</sup> Given the complexity of the concept of autonomy, this may seem like a feasible compromise.

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<sup>28</sup> For example, in Tom Beauchamp and James Childress’ classic bioethics textbook, the chapter titled “Respect for Autonomy” opens with, “The principle of respect for *autonomous choices* of persons runs as deep in the common morality as any principle...” (101, emphasis added). In bioethics and medical practice, patient autonomy is typically understood in terms of uncoerced decision-making.

In the U.S. healthcare system, the presumption in favor of the general autonomy of adult patients (in the global/programmatic sense previously discussed) is practical for providers and generally protective of patients' rights. Many providers simply do not have the professional bandwidth to get to know their patients on more than a superficial level, and rigorous evaluations of each patient's level of autonomy competency would be neither feasible nor useful in most cases. Hence, as long as patients do not exhibit cause to question their competence, they are generally assumed to have the ability and right to make medical decisions on their own behalf. In these circumstances, a decision is considered autonomous if it is arrived at through the process of informed consent. By choosing amongst available care options or consenting to an intervention, patients may be thought to exercise the skills that autonomy requires (constitutive cultivation), thus becoming more autonomous. By the same token, the choice itself may be taken as evidence of a patient's existent autonomy because it demonstrates a concrete instance of active participation in their own healthcare—which has now come to be an expected function of autonomous persons. Hence, this approach presumes that providers can easily protect and promote patient autonomy simply by obtaining the right kind of endorsements (e.g. informed consent).

Autonomy-as-autonomous-choice fits easily within the new paradigm of patient empowerment. In contrast with the dated paternalism of "doctor's orders" and "doctor knows best," patients are increasingly provided with tailored information and resources

designed to facilitate independent deliberation about available treatment options and acceptable risk/benefit ratios. Rather than simply being recipients of care, patients are now encouraged (and even expected) to play a more assertive part, and are commonly reconceptualized as “partners,” “consumers,” or “decision makers.” They are entreated to be more active participants in their health and healthcare not only in the clinical encounter, but also by performing recommended self-care and self-surveillance practices as a part of their regular daily routines (often characterized as making “healthy lifestyle choices”). To promote this shift in perceptions, the provider role has likewise been reconceptualized to make room for cooperation and partnership between providers and patients. This is exemplified in the increasingly popular model of “shared decision-making (SDM),” which is touted as a “patient-centered” approach to healthcare where “clinicians and patients work together to make optimal health care decisions that align with what matters most to patients” (Barry et al.).

Providers are now increasingly cognizant of the fact that (some) patients have more avenues than ever for holding providers accountable for behaviors and practices they find unacceptable or unsatisfactory.<sup>29</sup> Patients are invited to complete surveys and reviews of their healthcare experiences. They are told that they can speak with a patient advocate, research subject protection officer, or institutional review board member at

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<sup>29</sup> It should be noted, however, that not all patients are “empowered” to the same degree by these factors. English fluency, health literacy, race, gender, education, and socioeconomic status may all influence the extent to which patients are aware of their options and feel empowered to be assertive about grievances.

any time if they have concerns or complaints. Lawyers specializing in medical malpractice abound, often willing to take on patients' cases without payment unless a desirable verdict is rendered. And arguably, the cornerstone of this heightened attention to patient autonomy is the informed consent document, which is utilized both as a method of protecting patient autonomy as well as legally documented evidence of it.

Because of these efforts, some patients do report that they feel more respected, informed, and in control of their health—all of which may correspond with greater patient autonomy. But this is, by far, not the universal impression. Individuals' experiences in healthcare and medical research are extremely variable, but they fluctuate in some predictable ways correlating with certain aspects of personal identity, such as race, gender, socioeconomic status, education level, and availability/type of insurance coverage. Inadequate levels of health literacy are a pervasive problem that can undermine autonomy even while patients make choices that appear to be "free" and "informed." Patients who encounter the healthcare system in the midst of a health crisis are also likely to make care choices that are not fully autonomous because they are burdened or coerced by the circumstances of their illness. For instance, in emergency cases, availability and proximity of healthcare services (such as ambulances and hospitals), or the dictates of the patient's insurance policy, may be greater determinants of the type of care the patient will receive than personal preference or choice. Similarly, fear or debilitating pain may lead patients to choose immediate relief at the cost of

serious long-term health consequences—a decision they may later regret or feel alienated from. In other cases, the severity of their condition may require an urgent care choice that will not permit the patient to take the time she would otherwise require to deliberate and come to a decision. In situations of this sort, individuals may make healthcare choices in ways that appear to be “active” or “engaged,” but which may in fact fall substantially short of autonomous.

The further equation of autonomous choice with informed consent is predicated on the assumption that giving consent truly *is* a reflection of the patient’s unconstrained process of educated, critical reflection about the available treatments/services and how each aligns with her own values, preferences and goals. In reality, however, giving consent does not guarantee autonomy any more than clicking a mandatory box marked “Yes, I agree to the Terms of Service” guarantees that a consumer has actually opened (much less read and endorsed) the pages of fine print that precede authorization to use a certain product or service. While informed consent *can* be an expression of autonomous choice, it is not one by definition. As O’Neill points out, “By insisting on the importance of informed consent we *make it possible* for individuals to choose autonomously, however that it is to be construed. But we in no way guarantee or require that they do so” (37, original emphasis).

Drawing on the work of Charles Taylor, Natalie Stoljar claims that a relevant distinction here is that “autonomy is an exercise concept, whereas informed consent is

an opportunity concept" ("Informed Consent" 381). An opportunity concept connotes chances or choices that are open to a person, and that she may choose to (not) pursue them without external constraint. But while having choices is generally valuable to autonomy, it is not sufficient for it. As Stoljar argues, autonomy does not fully blossom as an opportunity concept. To be autonomous requires not only having (or even making) choices, but having a certain capacity for (and proficiency in) understanding and evaluating the options, comparing the opportunities and possible consequences with one's values, trusting one's judgment, and ultimately acting in ways that feel authentic and resonate with one's sense of self.<sup>30</sup> By contrast, "Informed consent normally requires weighing the costs and benefits of a certain medical procedure, and this weighing up can be adequately performed by a weak evaluator. It does not require the agent to make qualitative discriminations among values" (Stoljar "Informed Consent" 382). That is to say that the exercise of autonomy is different from the exercise of agency, and both may actually be significantly more difficult to accomplish when persons are sick, overwhelmed, or vulnerable, as they often are when approaching significant medical decisions. Thus, Stoljar criticizes that under autonomy-as-informed-consent practices, the decisions that patients make may be legally effective, but it cannot be assured that they have really been made autonomously.

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<sup>30</sup> These sorts of descriptive criteria are common in accounts from Diana Meyers, Marilyn Friedman, and many others. In this case, Stoljar endorses a substantive account of autonomy, which accounts for the inclusion of the criteria of trusting one's judgment.



Admittedly, it is more difficult to insist on the utilization of a more robust sense of autonomy and a less commercial, transactional view of the provider-patient relationship within a social climate so accustomed to thinking in these terms. Earlier in this project, I described the relationship between autonomy (especially autonomy as a right) and the related notions of liberty, property, individuality, and choice. Combined with the historical precedent of treating the body as a form of individual property, the concept of patient autonomy in medicine and bioethics has drawn from this tradition, coming to be understood as a primary patient right, often treated as synonymous with choice over what happens to one's own body. This also mirrors the importance of choice in popular culture, which is strongly correlated with agency, identity, and consumerism. Persons are encouraged to express their individuality, demonstrate their values, pursue their ambitions, and connect with others through the avenue of choice—including (and sometimes especially through) purchasing decisions. Choices such as where one shops, what brands one is loyal to, what social projects or causes one endorses, and the outward persona that one cultivates through social media are all tools for curating identity and a lifestyle of one's choosing. So, as O'Neill argues,

One plausible source of... the triumph of the minimal conception of individual autonomy that identifies it with informed consent requirements, may be that there is one presently prized domain of life in which informed consent

requirements are often seen not only as necessary but also as sufficient for ethical justification. This is the area of consumer choice. (47)

This connection between choice and autonomy in medicine is further reinforced through media like direct-to-consumer advertising for healthcare services and pharmaceuticals, which encourage prospective patients to shop around for the best care and to “talk to their doctors” about new medical product choices they may have for disease management.

But medicine is not *only*, and should not *primarily* be, a commercial endeavor. Although there are certain economic realities that must be accounted for, the therapeutic relationship between physician and patient is foremost. Providers are charged with the stewardship of one of their patients’ highest goods: their health. Although persons may take it for granted in times of wellness, their health undergirds all aspects of their lives and can have a profound effect on what they can do and be, and on what possible futures are open to them. While patients can do many things to protect and promote their own health, when they are most vulnerable or feel least in control of their bodies, they turn to medicine for help.<sup>31</sup> Framing this as a business transaction between medical goods on offer and patient choice (where choice is typically dependent on ability to pay) does not do justice to the complexities of the situation. Conflating the patient role with the consumer role can mask patient vulnerabilities and the power

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<sup>31</sup> Of course, providers are not only called in when the patient is in the throes of debilitating illness. Preventative health is also important, although the emphasis on this in the U.S. is considerably less than what it could *or should* be.

asymmetries inherent to the relationship. As Campbell explains, “Illness brings to patients inescapable dependency on caregivers for competency, knowledge, skill, and care, and re-naming patients as ‘consumers’ or ‘clients’ will not change this fact” (Campbell 254). Yet, rather than acknowledging the role that vulnerability and dependence play in the clinical encounter (and the myriad effects they may have on patient decision-making), contemporary medicine aims to minimize these “complications” through its emphasis on choice and consent.

Yet, some ethicists have argued that there is value to reconceptualizing the provider-patient relationship as one between contractor and consumer. In this model, meetings between the two parties would take on “the character of two separate agents, each bringing their unique perspective to mutually chart a course of action” (Andereck 110). Taking a cue from consumer culture, they argue that such an approach primes providers to accept the motto that “the customer is always right,” which helps to ensure that patients actually have their voices heard and their choices respected. But more often than not, patients and providers are not on the sort of equal footing that this perspective implies. As such, providers cannot approach interactions with patients as they would approach a business meeting, where each party, representing and safeguarding its own interests, negotiates an acceptable agreement. Although there is a risk of paternalism, providers nonetheless have a unique fiduciary obligation to their patients. Both appreciation for—and fulfillment of—this duty may be distorted by a

contractor-consumer model of healthcare. The provider's role is not simply to present the patient with choices, goods, or services; it is also to care for and guide the patient through times of illness, disability, and wellness, and this sometimes requires exercising clinical judgment to prevent or mitigate possible harms. As such, Miller et al. point out, "Patient autonomy is not the same as consumer sovereignty... patients do not have a right to receive whatever treatments they demand and are prepared to pay for. Preference and the ability to pay may be necessary for access to medical care in our society, but they are not sufficient" (355).<sup>32</sup>

Still, patients who feel vulnerable in medical settings may have a desire to regain some of the control they feel that they have lost, so it is easy to appreciate that some would try to do this by asserting their rights (especially to have and make choices). The idea that patients have certain entitlements that can be backed up by legal enforcement if necessary can be appealing and protective for patients, although it can also complicate the delivery of healthcare. As William Andereck laments,

At times, in my intensive care unit (ICU), it seems that autonomy is being attributed the positive right to control every facet of medical therapy... some patients, and especially their families, become familiar with the monitors and learn the medical jargon. Soon they are demanding medications by name and

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<sup>32</sup> I would like to say more about this particular aspect, but I am not able to do so here. It will have to suffice simply to mention that within the current U.S. healthcare system, severe economic disparities prevent many people from seeking medical attention. And people who do seek care, especially emergency care, are often plagued by lingering medical bills that are difficult to pay and place significant burdens on them that constrain other aspects of their lives (there is also evidence that financial stress negatively impacts health, thus perpetuating the cycle).

insisting on various procedures. Our medical residents can find themselves in the role of a short order cook, with a patient's surrogate insisting on tube feeding with a course of dialysis and a side of Vancomycin. (111)

But the ability of a patient, or her surrogate, to choose between treatment options or make a litany of demands does not, by itself, amount to autonomy—even if those demands are met. Rather, often times what these demands represent is not autonomy, but an effort on the part of patients or their loved ones to wrest back some feelings of control and usefulness in the midst of uncertainty, vulnerability, or feelings of powerlessness.

Unfortunately, it is not infrequently that the reality of the patient experience runs contrary to what persons have been conditioned to believe about their level of autonomy, choice, and control in healthcare settings (or in their lives in general). People are told that they have more choices than ever when it comes to their health or healthcare providers, that they are “in charge” of their health, or that they should feel “empowered” to ask (or even tell) their doctors about new drugs or interventions. Yet despite some contentious claims that advertising (or visits and incentives from drug reps to healthcare providers) performs a valuable informational role in healthcare, its primary purpose is still to stimulate demand, not promote autonomy, while encouraging persons to see themselves as potential patients. This can be seen most clearly in the areas of cosmetic surgery and in the marketing of so-called “lifestyle

drugs” for conditions such as baldness, acne, and erectile dysfunction. Even for more serious health concerns, such as high blood pressure or type II diabetes, drugs are marketed to patients under the guise of choice and empowerment (namely, the choice of the patient’s preferred drug—if they have already made the decision to use pharmaceuticals to treat such conditions, rather than choosing self-care habits, such as moderating their diets and increasing their activity levels). But again, as Stojar has argued, having and making choices is not the same as autonomy; it is simply agency. It plays a role in autonomy, but it is not a substitute for it.

### **Issues with Informed Consent**

Autonomy-as-informed-consent fits naturally with this emphasis on choice and consumerism. By using a special type of documented authorization ritual as a proxy for patient autonomy, it aims to empower patients while simultaneously providing medical institutions with a useful metric for identifying and quantifying these concrete instances of “punctate [patient] decision-making” (Kukla) and protecting the institution from liability. As such, a primary concern for bioethicists, healthcare administrators, and medical professionals is *whether* and *by what process* patients give informed consent, which then serves as the evidence of whether patient autonomy has or has not been respected. Less frequently is the question raised as to whether the degree of priority that autonomy (generally) and informed consent (specifically) receive is in proper

proportion to the myriad other concerns and values relevant to patients in these circumstances.

On the part of providers, especially for consent to research, there are regulations in place that dictate what information patients must be presented with in order for the decision to be considered “informed.” For instance, in the United States, the Code of Federal Regulations (CFR) requires that potential research subjects be given information about research studies “in language understandable to the subject or the representative” (21 CFR §50.20). Here, the term “information” encompasses both the informed consent documents provided to potential subjects and the oral communication that is part of the consent conference. Providers and investigators are expected to engage patients in a thorough discussion of the proposed treatment or study and permit them adequate time to ask questions and reflect on the choice before them. To be “understandable,” the information must not only be presented in a language that the subject is fluent in, but also in a way that is comprehensible to individuals without specialized medical knowledge. For maximum comprehension, the general guidance is that medical information should be written at a sixth to eighth grade reading level, without the use of medical jargon. This practice is advised in the hopes of improving clarity and avoiding burdening patients (who may already be experiencing confusion, difficulty focusing, or heightened stress due to their current medical situations) with a level of

language complexity that contributes to anxiety and misunderstandings about the information presented.

Unfortunately, most consent documents are written by investigators or staff whose level of comfort with this type of information and medical language (combined with their general familiarity with the practices described and their higher levels of specialized education) tends to be considerably higher than that of the patient audience for which they write. Most do not confirm the reading level of study documents before sending them out for review board approval or patient use, and most review boards or administrators do not reject such consent forms on the basis of comprehensibility or readability.<sup>33</sup> Furthermore, while guidance indicates that patients should have sufficient time to consider the proposal, the consent conference for a given treatment or research plan may take just a few minutes to a few hours, depending on complexity.

On the part of patients, the expectation is that by giving consent, a person makes a choice of her own volition, with the confidence of conviction in the validity of her own reasons. She may, if she likes, take the opinions, values, and preferences of others under advisement, but ultimately she is expected to decide for herself. If a patient's

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<sup>33</sup> At some institutions, measures are taken to reduce document lengths (by removing line breaks, minimizing margins, reducing font sizes, and scrapping content that is deemed less essential) in the interest of conserving institutional resources or in order to fit better with internal document storage practices. For example, many institutions are required to keep physical copies of documents on file for several years, and this presents storage space issues. Reducing the document sizes facilitates storage, without consideration for the impact on patients. These measures crowd content, diminishing the clarity and readability of these documents, and can themselves overwhelm and frustrate patients. The visually impaired, people with dyslexia, people whose native language is not English, and people with limited formal education may be particularly vulnerable.



consideration for (or deference to) others is perceived to be beyond the acceptable threshold, coercion may be suspected or the patient's competence and may be called into question. But otherwise, as long as the appropriate information is exchanged and the appropriate patient competencies may be reasonably presumed, this encounter is all that is typically required to fulfill the obligation of respect for autonomy.

But as Sherwin argues, there are a variety of macro-level factors (e.g. laws, institutional policies, socio-cultural attitudes, and power structures) that have bearing on particular contexts of patient consent, and which may influence patients and their decisions (and undermine patient autonomy in a more robust sense) even before the moment of decision ever arrives. These factors are typically downplayed by conventional informed consent practices that posit that:

Patient decisions are considered autonomous if the patient is (1) deemed sufficiently competent (rational) to make the decision at issue, (2) makes a (reasonable) choice from the set of available options, (3) has adequate information and understanding about the available choices, and (4) is free from explicit coercion toward (or away from) one of those options. (Sherwin 26)

Sherwin's criticisms of these criteria are quite compelling and help to identify broader issues of the conflation of autonomy with autonomous choice and informed consent, so I will discuss them at some length here.

The first criterion implies a standard (competence) that lacks clear guidelines. Sherwin argues that the guidelines that are employed (and the providers who employ them) are often influenced by historical and current practices of oppression and marginalization that impact the accepted picture of what competence is, who can be competent, and under what circumstances.<sup>34</sup> As such, it is not uncommon for a person's competence to be called into question because she does not agree with her provider's treatment proposal. This is particularly true for women, the poor, people of color, and the disabled. By contrast, it is less likely that the same patient's competence would be questioned if she acquiesced to her doctor's proposal, whether or not she actually acted autonomously. Furthermore, in the context of informed consent, a patient's perceived reliance on the opinions or considerations of others (such as a spouse or child), or unwillingness to state a preference (e.g. preferring that the provider tell the patient what course of action to pursue), is a red flag for providers that the patient may not be competent. But as I have discussed, since we are relational beings whose identities, goals, and preferences are bound up with our connections to others, it is not realistic to expect patients to make "autonomous" choices without considerations of these factors. In fact, asking patients to choose a course of action in isolation from supportive connections to others (even if the patient has no loved ones upon whom she depends,

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<sup>34</sup> These considerations for competence mirror the similar criticisms of the ideal of autonomy discussed in Chapter 3.

and instead prefers to depend on her provider's expertise) may actually undermine autonomy and increase patient distress and suffering.

The second criterion obscures the fact that the "available options" presented to patients have already been pared down by external factors such as research funding, medical research publication criteria, medical school curricula, institutional policies (such as insurance coverage, hospital guidelines, etc.), and a variety of other "background decisions" (Sherwin 26-27). Sherwin argues that this is problematic not only because it constrains opportunities for patients, but also because people in oppressed groups, whose opportunities in many aspects of life are already restricted, "tend to be underrepresented on the bodies that make these earlier decisions" (27). And for patients who are uninsured or underinsured, or who lack the independent financial resources to pay for their care, the particular decision to participate in research studies (especially disease management studies for the care of severe or chronic illnesses such as diabetes, hypertension, or cancer) may not reflect a patient's understanding, desire to contribute to science, or considered evaluation of the risk/benefit distribution of the study. Instead, the decision may be based on the incentives that the study provides, including that the medications and clinical care that the patient will receive during research participation is typically less costly (or even free), and that study participant retention strategies often include financial compensation and/or the arrangement of transportation for participants to and from appointments. Thus, for some patients,

consent to research may be based primarily on the understanding that, despite the risks, it is the patient's best, or perhaps only, option to receive medical care.

This criterion also implies that competence or rationality requires patients to choose from the options presented to them; hence refusal to choose, or refusal to choose from the presented options, may present a conundrum for providers. While the term "informed consent" implies the possibility of "informed refusal," this possibility tends to be attenuated in actual practice. As O'Neill points out, "what is misleadingly spoken of as 'patient autonomy' masks the fact that the patient's role is only to say 'yes' – or to do without treatment" (26). There are an extraordinary number of reasons and circumstances that precipitate a refusal of medical care, including religious beliefs, concerns about medicalization, distrust of medicine, a commitment to homeopathic healthcare, personal values, cost, lack of insurance, concerns about how it will impact loved ones, and so on. Yet, while refusal is permitted in theory, in practice it has often resulted in deeper scrutiny of a patient's competence, which may include legal intervention and ultimately the overriding of a patient's wishes.

The third criterion is open to similar objections as the second: the available information has already been filtered through institutional practices that are not sufficiently representative of, or attuned to, the interests of people in marginalized groups. As with the first criteria, this one also depends, to a certain extent, on the subjective interpretations of the provider. In this case, the provider has the discretion

(and the obligation) to determine what information is relevant, both in general and with regard to specific patients. Unfortunately, relevance considerations are often influenced by the provider's perspective and experiences, as well as her impression and opinion of the patient's needs. This means that providers can be more or less accurate in gauging relevance for patients, and may be better at doing so for patients who have similar characteristics and experiences to the provider (for example, there may be greater or lesser degrees of commonality between the provider and patient along the lines of gender, race, socioeconomic status, education, etc.).

In addition, for the third criterion, there is also the question of the patient's understanding of the relevant information. A person's level or degree of understanding is notoriously difficult to gauge and this is a persistent problem in medicine and research. As defined in Title V of the *Patient Protection and Affordable Care Act of 2010*, health literacy is "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services in order to make appropriate health decisions." However, according to survey data from the National Assessment of Adult Literacy (NAAL), only 12 percent of U.S. adults have what is considered to be a "proficient" level of health literacy, while approximately 35 percent have health literacy levels that are considered "basic" or "below basic" ("American's Health Literacy"). While individuals may be slightly more likely to have "intermediate" or "proficient" health literacy if they are white, college educated, under

age 65, and insured through employer or private health insurance, the data nonetheless demonstrates that “basic” or lower health literacy is prevalent in the United States, affecting a huge proportion of Americans across all races, education levels, age groups, and types (or lack) of insurance coverage. As such, it constitutes a major public health concern and is a significant impediment to patient autonomy.

During a consent conference or clinical encounter, patients may feel self-conscious or embarrassed about their own level of health literacy. For these reasons, they may not take the time needed to read and understand medical documents (e.g. they feel rushed, or worry about the time it takes them to read a document, or they may not be proficient readers). Patients may not ask questions, or may feel pressure to consent even if care choices are presented in a neutral fashion (e.g. “my doctor must be asking me because she thinks it’s a good idea” or patients may worry that their refusal will disappoint providers or hamper research progress). Due to stress, the complexity of the diagnosis or procedures, or a patient’s need for time to process their current circumstances, patients’ or families’ levels of comprehension in these encounters may be much lower than providers anticipate. Furthermore, in addition to the direct impact it has on patient autonomy, according to the U.S. Department of Health and Human Services (HHS), low or suboptimal health literacy has been correlated with decreased likelihood of seeking medical care (e.g. to avoid shame and confusion; due to inability to recognize when a condition requires medical attention; due to a lack of awareness of

available preventative care services; or due to financial constraints), worse health outcomes (e.g. due to seeking treatment at more advanced stages of disease, or an inability to understand and adhere to treatment recommendations), and higher treatment costs and financial burdens (e.g. as related to greater use of emergency services, being uninsured or underinsured, and decreased ability to pay medical bills). Hence, if the measure of autonomy in bioethics and medical practice is the ability of a patient to provide informed consent, and the overwhelming majority of adults in the United States fall below the threshold of proficiency required to efficiently utilize health data and services to make medical decisions, then informed consent rituals cannot be accurately measuring or protecting patient autonomy.

In a similar vein, Beauchamp and Childress cite a study (just one of many similar instructive examples) in which 90% of participants in an oncological clinical trial reported feeling “well informed” and satisfied with the informed consent process, although roughly 75% of them demonstrated a failure to understand certain key elements of the study that were explained to them, such as the fact that it involved experimental and unproven interventions, and that they may not benefit in any medical way from their participation (Beauchamp & Childress 131). The phenomenon is so common in human research that it has been given the name “therapeutic misconception.” This refers to the tendency of patients and families to believe that research participation will secure them priority access to safe and effective new

medicines, or that by participating they are guaranteed to receive a study intervention rather than placebo or standard of care. This misconception demonstrates an inappropriately developed understanding of the nature of research and the level of risk it entails, which often may be higher than the risks of standard clinical care. While this misconception may affect any patient, those with lower levels of health literacy and those whose primary language is not the same as the provider's are especially susceptible.

But this problematic gap between information provided and information understood it is not limited to research contexts. As O'Neill argues, in the informed consent ritual, patients only agree to a treatment or research *proposition*. Unfortunately, due to limited medical literacy, lack of experience, or other factors, patients may not have a full appreciation for what procedures are necessary, or what consequences or outcomes are possible over the duration of care. They may be able to make a decision in the moment that a choice is required of them, but it is not clear that that decision represents an autonomous action in the sense that it supports the identities, relationships, and goals that are important to the patient. Bluhm puts it beautifully when she writes,

[L]earning what it is like to live with a demanding treatment regimen, with the side effects of a medication, or with the illness itself may make an individual more (or less) willing to accept the outcomes associated with her initially



preferred therapy. But these are not things that patients can be informed about during the course of an appointment with their doctor; they must be experienced in the broader context of the patient's life. Thus, patients will require time and experience, as well as information, to be able to determine both how their illness and its treatment will affect their values and goals" (Bluhm "Evidence-Based Medicine" 146).

Patients may be able to understand conceptually what they are agreeing to, but when it comes to the actual experience, they may find out that it is not exactly what they thought that they signed up for. Especially for complex and urgently needed treatments, such as oncology care, the first decisions often need to be made even before a patient or family has had the time to process the new diagnosis, its implications, and its possible meaning for their lives. As a result, patients and families may find themselves both figuratively and literally lost in the midst of a healthcare experience that is dauntingly unfamiliar and difficult to navigate, and where the seemingly split-second decisions they are asked to make may have life or death consequences. These problems are further compounded when patients and families have low health literacy or are not proficient in the common language. In these circumstances, though time may be of the essence, it is nonetheless unreasonable to expect patients or guardians to be able to give genuine informed consent to a course of action after simply being given an hour or two of explanation along with a forty-nine page consent document outlining all

possible treatments, contingencies and deviations that may occur over the next two years of treatment—all for a life-altering diagnosis that the patient has only just received.

Finally, the fourth criterion Sherwin discusses is useful in its recognition that coercion undermines autonomy. The problem, however, is that systematic oppression coerces patients in nefarious ways that are difficult to detect, describe, and combat, as we see with the first three criteria (Sherwin 27-28). There is also a possibility that the way that the healthcare system is structured and the circumstances under which patients encounter it may themselves have the effect of undermining autonomy. In the United States, preventative care and routine wellness visits are recommended for all persons, but the proportion of individuals who follow these recommendations is surprisingly small. Most of the time, patients do not engage with the healthcare system when they or their loved ones are well. There are very few circumstances in which healthy persons routinely utilize medical care (e.g. pre-natal care for expectant mothers, and post-natal care for mothers and newborns); instead, most medical encounters occur in response to the illness or injury of oneself or a loved one. This means that most patients are not very experienced with the medical system, and that most of their experiences occur during times of duress. Unfortunately, this inexperience and lack of familiarity often translates into a general lack of confidence in one's (medical) decision-making competencies. This is compounded when, especially in the event of very serious

illness or injury, a decision must be made expediently. Although it may be unavoidable (such as when a patient needs immediate surgery, or when cancer treatment must be started as soon as possible), the urgency with which a decision must be rendered can itself be coercive.

But even when a decision is not needed immediately, or a patient's condition is not serious, this lack of familiarity and experience may still be detrimental. This point hearkens back to the earlier distinction between autonomy as an exercise concept and informed consent as an opportunity concept, and the temporal component of this which has been alluded to. Whereas the former is an ongoing process best understood in the context of a life lived over time, the latter concerns a distinct episode of choice often evaluated in abstraction from that broader context. As Meyers has argued, there is a qualitative difference between making particular autonomous choices in certain circumstances (which she calls episodic autonomy) and being fully (programmatically) autonomous. She writes, "Autonomous episodic self-direction occurs when a person confronts a situation, asks what he or she can do with respect to it... and what he or she really wants to do with respect to it, and then executes the decision this deliberation yields" (Meyers 48). By contrast, programmatic autonomy entails a much broader, deeper, and long-term vision of who a person is or wants to be and how she wants to live, which is developed and remodeled as necessary over the course of a life.

For Meyers, a person who is autonomous exercises autonomy skills to the point of competency by employing them in both episodic and programmatic contexts. Specifically, instances of episodic autonomy provide an opportunity both to demonstrate and to strengthen the core competencies that contribute to overall, global autonomy. Likewise, being globally (programmatically) autonomous helps to ensure that a person's choices and actions are consistent with (and reflective of) her own identity, preferences, and goals. Hence, a person who is competent in this way generally experience a more-or-less fluid integration of her episodic decisions into her programmatic life plan. On the contrary, Meyers doubts that a person who is only ever episodically autonomous is genuinely autonomous in the fullest sense of the word. That is to say that it is extremely unlikely that a person could consistently make autonomous choices without some enduring sense of oneself and a general idea of how one's choices contribute to or detract from the kind of future that one is pursuing.

A significant concern for autonomy-as-informed-consent, then, is that it is not sensitive enough to these considerations to always allow providers to accurately ascertain whether patients are, or could be, autonomous in these circumstances. Informed consent represents a particular moment of choice, and this moment is typically understood in abstraction from the broader context of a patient's life. It cannot always be used to ascertain whether individuals have the experience, health literacy, or perspective to fully grasp the implications of their medical decisions—including the

impact that these decisions may have on identity and the future that is open to them after such decisions have been made. Thus, the current prioritization of “the *punctate decision*—a decision made in response to a discrete choice that can be understood in isolation from the rest of a patient’s health care” (Kukla 35) reinforces a static or “time-slice” view of a person that may not be useful in gauging whether a person is autonomous, either programmatically or relative to that episode.

Due to a lack of consistent interaction with the healthcare system over the course of one’s life, patients may not have sufficient opportunities to hone health literacy and medical decision-making skills. Thus, if persons have only few and sporadic opportunities to practice these skills, they may be less adept at anticipating how their care choices may impact their identity, relationships, and goals and may be less competent overall in exercising autonomy in these instances. Furthermore, especially when newly-diagnosed patients are tasked with managing chronic or life-threatening conditions, individual (i.e. discrete or punctate) medical decisions can have a cumulative impact over time. Deciding for or against certain procedures, medications, or research opportunities may preclude a patient from choosing or being eligible for other such procedures, medications, or opportunities in the future. Hence, there is an increased risk that such persons will regret their earlier choices or be frustrated with their outcomes or general care trajectory.

To further demonstrate some of the concerns with the traditional conception of patient autonomy, especially autonomy as autonomous choice, in the next chapter I will explore a paradigm case in bioethics in which this approach has been taken to its logical extreme. I critique Robert Veatch's arguments in his book, *Patient, Heal Thyself: How the 'New Medicine' Puts the Patient in Charge* (2008), in order to explore how patient autonomy, when understood in the traditional, individualistic sense (with its overwhelming emphasis on choice), can have an isolating and undermining effect on already vulnerable patients. In contrast to Veatch's approach of extreme autonomy, I will argue that persons are relational, and connections to others are essential during times in which identity may be called into crisis by the experience of pain or suffering. Thus, especially in difficult healthcare decision-making contexts, patients need relationships of support, empathy, and trust (not only with their friends, loved ones, and those in their social support networks, but also with providers) in order to act with autonomy—and these connections play an even greater role when patient autonomy is compromised. Connections with others play a crucial role in protecting and restoring patient identity and choosing care that fits the needs and goals of patients, which may help to alleviate suffering. Providers can foster these relationships by taking the time to understand patients' preferences, fears, and hopes, as well as by recognizing the importance of patients' connections to others, and by respecting (rather than undermining) the impact these relations have on patients' identities and choices.

## CHAPTER 8: AUTONOMY, SUFFERING, AND THE GOALS OF MEDICINE

Robert Veatch's work in *Patient, Heal Thyself: How the 'New Medicine' Puts the Patient in Charge* (2008) is a textbook example of the strong and narrow focus on "patient autonomy as autonomous choice" that has emerged from contemporary bioethics and medical practice. In this text, Veatch argues that a radical transformation of the patient role is currently underway in healthcare.<sup>35</sup> He writes,

We are in the early stages of what can be called 'the new medicine,' a medicine in which patients will recapture responsibility for their own health choices—including choosing their own therapies based on their own beliefs and values. It will be a world in which patients will, in a very real sense, have to heal themselves. (Veatch 4)

Veatch argues that the "new medicine" is patient-centered to an unprecedented degree because it shifts the balance of power strongly in patients' favor. But as I will argue, his focus on patient autonomy (primarily construed as free choice) actually comes at the cost of better understanding the complexity of the patient as a whole person in relation

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<sup>35</sup> Of the "new medicine," Veatch writes, "We are headed for a wholesale change—a medicine as different from modern, scientific medicine as the modern practice was from its primitive predecessors" (4).

to others. Veatch challenges providers' authority to act as the gatekeepers of healthcare, arguing instead that patients should be able to choose any type of medication, intervention, or care that they desire without provider interference or prejudice. In this new paradigm, the patient is "part consumer, part client, part customer, but especially whole person who is the senior partner in the relation with health professionals acting as assistants" (Veatch 17). This shift in power dynamics is based on the premise that "every medical choice requires nonscientific value judgments" (Veatch 4), and since, as he argues, providers do not know—and cannot be expected to know—what is in their patients' best interests, it should be patients' values and judgments, and not providers', that define health and dictate the terms of care.

Throughout the book, the way that Veatch characterizes modern medicine is extremely disparaging, describing it as "authoritarian," "tyrannical," and something that is "inflicted" on patients. In one particularly charged passage, he writes, "I was asked to assist in the *liberation* of Karen Quinlan from her *medical captors*" (Veatch 16, emphasis added). In this example, as well as elsewhere, Veatch presents a particularly pessimistic outlook on modern medicine, often insinuating that physicians are narrow minded, egomaniacal, and domineering—or, at the very least, naively and militantly committed to an enterprise whose values, ways and means they have not critically evaluated. As such, he intimates that patients have good reason to be skeptical of their providers' motives and any medical advice they receive. In addition, Veatch expresses



disdain for many current healthcare practices, such as prescription writing and informed consent, arguing that they are power moves by the medical establishment that undermine patient autonomy by reinforcing the authority of the provider and manipulating or restricting patients' free choice. He is also vehemently opposed to the continued use of medical terms or colloquialisms such as "doctor's orders," "doctor knows best," "hospital discharge," "medically indicated," "medically necessary," and "treatment of choice," which he views as anachronistic carry-overs from a bygone time. He argues that such language is inappropriate because it attributes medical authority to providers or institutions and disguises value-laden medical opinions as scientific fact, both of which undercut patient autonomy.

Veatch's primary thesis is that although medicine may be undergirded by scientific facts, its translation into healthcare practice is fundamentally value-laden; therefore, to protect patient autonomy, it must be patients' values that are at the helm. It cannot be left up to individual physicians—or even the consensus of all healthcare providers, scholars, and administrators (which he refers to as "the tyranny of experts"(256))—to determine what medications, procedures, or courses of action are best suited to patients. He argues that a doctor is an "expert on the body" (Veatch 78), but is not qualified by virtue of this expertise to speak to normative questions (such as about what outcomes are "good," what patients "should" do for their health, and what is in patients' best interests), which he claims are not proper to the field of medicine.

Such questions, he argues, are better left to persons in religious, philosophical, and other domains that are expressly concerned with values.

Additionally, since we live in a pluralistic society that is tolerant of a wide array of beliefs and values, Veatch argues that this tolerance and general openness to the pursuit of diverse conceptions of the good should extend to the practice of medicine as well. In the new medicine, he claims that patients will demand (and receive) wide latitude to make medical choices that align with their own preferences and commitments, and they will be allowed to pursue services or treatments of their own choice regardless of conventional medical standards or guidelines. It will be up to society, not providers, to ban only what it finds “intolerable,” otherwise leaving patients to make healthcare decisions according to preference and conscience. He claims that this maximization of choice actually eliminates the need for informed consent because instead of acquiescing or dissenting to treatment options that doctors choose, patients will demonstrate their own autonomy by demanding the treatments they prefer. Providers will, essentially, know that patients’ choices are autonomous simply by virtue of the fact that patients have chosen them.

To facilitate this objective, Veatch suggests that patients will no longer be assigned to certain providers or institutions based on insurance coverage, proximity, or default; rather, patients will choose their own providers on the basis of “deep values pairing.” This arrangement would require providers, insurance companies, and

healthcare institutions to publicize their fundamental values or moral orientation so that they are transparent to patients. It would also require healthcare providers to clearly spell out their care philosophies, including being explicit about what types of services are—or are not—on offer to patients. By this method, Veatch argues that, “when unconscious bias and distortion occur, as inevitably they must, they will tip the decision in the direction of the patient’s own [value] system” (107), because provider and patient will have already come to a prior cursory agreement on which values ought to prevail.

Veatch admits that this value pairing system will be considerably difficult to implement, but he is hopeful that it can be done. To this end, he points to some organizations that he believes have begun to undertake this project (e.g. “Feminist health centers, holistic health clinics, and the National Institutes of Health Clinical Center” (108)). He proposes that a Catholic HMO, for instance, could identify its key philosophy and commitments and use this information to explain to the public how it decides which treatment options it will provide. Individuals who endorse this approach could then elect to have their care provided by the Catholic HMO. Veatch writes, “Such value pairings obviously will not match perfectly, but they should at least place provider and patient in the same general camp” (109). In other words, while medicine cannot purport to be value-neutral, by being candid about the values and commitments that govern the type of care and services offered, healthcare providers can make it

easier for patients to recognize the effects and limitations of different moral or professional biases. This would allow patients to be savvier in choosing providers and insurance plans, presumably making selections that most closely resemble their own particular value profile, thus empowering patients and enhancing autonomy.

It should be noted that although Veatch eschews the use of informed consent, his approach is nonetheless consistent with the idea of autonomy-as-autonomous-choice that I critiqued in the previous chapter. There, I argued that in practice, autonomy has been distilled down to the more manageable “autonomous choice,” which, for the sake of practicality and convenience, has been even further reduced to “informed consent.” Thus patients are considered autonomous when they give or withhold permission for a particular treatment or research project. But Veatch’s criticism is that informed consent only allows patients the choice of consenting to a singular proposition of care, which has been pre-determined for them by their physicians from all the available alternatives. Consent, he argues, is tantamount to acquiescence to the authority of the doctor to make these background decisions on behalf of patients, which he finds outdated and

paternalistic.<sup>36</sup> Veatch's approach eliminates the need for informed consent because it presumes that patients have knowledge about (and access to) the entire breadth of available treatment options, and this permits them to make choices more freely (outside of the influence of their doctors' values), which he equates with greater autonomy.

In the next chapter, I will use Veatch's work to further elaborate on the problems that arise when choice is used as the standard for patient autonomy in bioethics and the practice of medicine. Veatch's work demonstrates the risks of continuing to develop and pursue the conventional, highly individualistic approach to patient autonomy. Critiquing his arguments—where patient choice and autonomy are pushed to the extreme—provides the opportunity to contrast this approach with the benefits of a more relational one. However, before I can delve further into this comparison, I would like to detour towards a more thorough discussion of the nature of suffering and the goals of medicine—considerations that are conspicuously absent from Veatch's work. Suffering, I argue, is a threat to patients' health, wellbeing, and autonomy. This is a significant component of the patient experience that seems to be missing from Veatch's

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<sup>36</sup> It is interesting to note that in "Abandoning Informed Consent" (both the 1995 article, and the chapter in his 2008 book), Veatch argues that informed consent is a "transition concept," which he understands as a placeholder idea/practice that functions as an intermediary between the old way and the more robust, innovative, and appropriate way of the future. But if it is a transition concept, it is a fairly long transition. Informed consent has enjoyed pride of place in medicine and medical ethics for more than seventy years now, where its primacy was asserted firmly in the Nuremberg Code in 1947, was reconfirmed in the Declaration of Helsinki in 1964, and incorporated into the Belmont Report in 1979. Even Veatch's own assertion that it is transitional was repeated from 1995 (article) to 2008 (book), while informed consent continues to be endorsed and utilized in medicine and medical ethics. In this project, I critique the idea of autonomy *as* informed consent, but I am not opposed to informed consent in principle. Informed consent is valuable to patients and useful to healthcare providers; thus, both the document and the ritual do have benefits, but being a way to "measure" autonomy is just not one of them.

account. Although it is the aspiration of medicine to relieve patients' suffering, this cannot be effectively done without an adequate understanding of the effects of suffering not only on the body, but also on patients' goals, values, and sense of self. I will argue that, especially in times of suffering, recognition of patients' inherent relationality is essential to good medical care. Therefore, practices which isolate or alienate patients from these relationships increase suffering, undermine autonomy, and make medicine less effective in caring for patients.

### **Suffering and the Goals of Medicine**

The idea that medical professionals have an obligation to try to relieve their patients' suffering is generally taken for granted. Calling to mind the etymology of the word "patient" (from the Latin, "to suffer"), Thomas Lee asserts that, "Suffering is, of course, inherent to medicine... But some of that suffering can be avoided, much of it can be reduced, and there is no ambivalence in healthcare about the goal of reducing suffering" (1575). Unfortunately, while many agree that the relief of suffering is an obligation—or at least a primary aspiration—of medicine, the means and extent to which providers can—or should be expected to—honor this calling are not always clear.

On some accounts of the goals of medicine, the relief of suffering is portrayed as a byproduct of the medical encounter: as physicians care for and cure the body, suffering that is derived from pain and illness is also relieved. In these cases, no special attention to suffering-in-itself is required; if the suffering is of the body, it should be

reduced or eliminated by measures that restore bodily wellness or integrity. Unfortunately, from this perspective, “chronic, protracted pain and unremitting suffering experienced by patients is a symbol of medical failure” (Campbell 247). Such confrontations with the limits of medicine’s ability to cure have historically led to the neglect or abandonment of affected patients. When unresponsive to available treatments, patients’ suffering came to be seen as psychological, insignificant, or outside the purview of medicine.

By contrast, on other accounts of the goals of medicine, the objective to relieve suffering receives such pride of place that, as Courtney Campbell puts it, “medicine has added to its goal of relieving suffering an aspiration to banish suffering from the human condition” (247). This ambition can be seen reaching across all medical specialties, from oncological therapies using genetic interventions to change patients’ own immune cells, to predictive tests to assess risk of future illness, to new assisted reproductive therapies, elective cosmetic medicine, and increased prescriptions of opioid medications for acute and chronic pain. For proponents of physician-assisted death and euthanasia, the obligation to relieve suffering is so strong that, in the absence of medical capacity to do so while sustaining life, it is considered morally acceptable—and even morally obligatory—to respect patient requests to hasten death.

Despite troubling population level trends in disease-related morbidity and the fact that many U.S. citizens and residents still have inadequate access to needed

healthcare services, as a whole, our culture has a very high expectation of health. We live during a time of increasing medical proficiency, which is, for many of us, coupled with heightened standards of living, better access to nutrition, education, and healthcare, and other contemporary privileges that have improved population health and increased longevity across the board. As a result, in contrast with the way that illness, injury, and death have been understood for most of human history, we have come to perceive these parts of life as unusual and unnatural. Such things now catch us off guard, often presenting as unexpected and unwelcome interruptions to our regular lives.

These “intrusions” feel unnatural and bewildering because we have taken for granted the degree to which we are really in control of our health. As Robyn Bluhm argues, rather than understanding vulnerability as a fundamental part of the human experience, we rationalize that illness and disability are caused by personal faults or unexpected misfortunes, and thus are exceptions to the norm. She writes,

in order to continue to believe that health is our natural state... we distance ourselves from those who are ill by finding other differences between ourselves and them, and explaining the cause of their illness in terms of these differences. Maybe they smoked, ate badly, or had a family history of their condition. These differences allow the healthy to remain ignorant of the fact that they, too, are vulnerable to illness. (Bluhm, “Vulnerability” 157-158)



Especially for those of us who have had the incredible fortune to enjoy good health for most of our lives, when we find ourselves in the position of the patient, it is not uncommon to feel betrayed by our bodies or as if the illness “came out of nowhere.” Our immediate concern is the expedient return to status quo, and we are often willing to try a vast array of potential remedies to hasten the process. For instance, while the common cold is, for most of us, a brief and typically inconsequential illness, the degree to which it is perceived to frustrate our lives is usually quite high (that is, we often feel quite put out by having to miss work or cancel social engagements, and by our sub-optimal performance and general malaise). While all that is typically needed for recovery is basic self-care and the passage of time, during such times of illness, we are often keen to engage in more “active” health rituals (even those which may be of unknown or unproven benefit, like high dose vitamin supplementation) that are purported to prevent or shorten the duration of discomfort in order to regain the feeling of control over our bodies more quickly.

Yet despite contemporary medicine’s inability to prevent or cure something as mild and transient as the common cold, when it comes to more serious illnesses or injuries, our confidence in medicine’s ability to cure remains extremely high. We expect that when significant health events happen that throw off our equilibrium and disorient us, we can rely on healthcare professionals to know what to do—and this is often true. But even with the best providers, facilities, and technology available, medicine provides

no guarantees. Despite outward appearances, the medical field is in an intimate relationship with uncertainty. Unfortunately, this uncertainty—when both patients and providers confront it—can be a source of additional discomfort and even suffering.

Because, as I will argue, suffering is a threat to autonomy, medicine’s efforts to relieve suffering—whether undertaken intentionally and directly, or only indirectly as a consequence of medical intervention—play a critical role in protecting and promoting patient autonomy. How providers understand the nature of suffering and their role in relieving it also has a huge impact on patients’ perceptions of the quality and effectiveness of the care they receive. Also important is how providers and patients communicate about their goals for any particular clinical encounter or ongoing care regimen, which helps to clarify expectations, reduce misconceptions, and improve health outcomes.

To understand the specific goal of relieving suffering, it is helpful to examine the overarching goals of medicine. Drawing on the Hastings Center’s report on this topic, I discuss how medicine (in general) and providers (in particular) approach the issue of suffering.<sup>37</sup> This discussion takes the Hastings Center’s outlined goals of medicine as its starting point, especially the objective of, “The relief of pain and suffering caused by maladies.” Then, drawing on the work of Eric Cassell, I will describe how suffering affects patients’ sense of self, identity, and future, and the impact this can have on

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<sup>37</sup> The Hastings Center Report on the goals of medicine is, admittedly, a bit dated by this time, although it remains one of the most direct and highly cited works on this topic.

medical decision-making. I will then build on Cassell's work in order to demonstrate why conventional approaches that emphasize individualism and choice while undervaluing relationality are inadequate to the task of encouraging and ensuring patient autonomy and relieving suffering.

In 1996, the Hastings Center published a special supplement to their bimonthly journal entitled, "The Goals of Medicine: Setting New Priorities." As a collaborative project that included contributions from the World Health Organization and participants in working groups in fourteen countries, the report was the culmination of four years of discussions between scholars and medical professionals who sought to refine the goals of medicine in light of modern sensibilities, available technology, and medical possibilities. The result of the project was the identification of the following four items as the primary objectives of sound medical practice:

- (1) The prevention of disease and injury and promotion and maintenance of health.
- (2) The relief of pain and suffering caused by maladies.
- (3) The care and cure of those with a malady, and the care of those who cannot be cured.
- (4) The avoidance of premature death and the pursuit of a peaceful death.

("The Goals of Medicine")

Relief of suffering is prominent amongst these goals, and in specifying concern for suffering as it relates to malady, the report makes an effort to distinguish between the sources of ailment and distress that medicine can reasonably be expected to address and those that are beyond its scope. Thus, the idea of “malady” plays a central part in framing the discussion.

As the goals indicate, medicine is oriented toward the promotion and restoration of health; malady, by contrast, is perceived as an antagonist of health. This is evident in the Hastings Center’s definition of health as, “the experience of well-being and integrity of mind and body... characterized by an acceptable absence of significant malady” (S9). Accordingly, all four goals broadly aim at minimizing the impact that malady has on a patient over the course of her life. The definition that the Hastings Center offers for “malady” itself is quite broad. As an umbrella term meant to cover a range of conditions, “malady” refers to a disturbance in the expected physical condition of the patient (e.g. illness, injury, abnormality). In this way, the term functions as a useful catchall for the different species of bodily concerns that medicine aims to attend to and alleviate, and thus it reflects a traditional understanding of the role of medicine (i.e. the care and cure of the body). Suffering, then, appears to be something that can accompany malady as a sort of consequence of experiencing it, depending on the severity of the malady and the degree to which it frustrates the lifestyle of the patient. This leaves room for the possibility that not all patients that experience malady will also

experience suffering, and implies that the care of a malady should also lead to the relief of the related suffering for those who do. By this interpretation, medicine treats maladies, but suffering is mitigated as a side effect of the medical encounter—that is, the suffering itself is not the object of medical intervention.

But later in the discussion, the authors expand their characterization of malady to, “that circumstance in which a person *is* suffering, or at an *increased risk* of suffering an evil (untimely death, pain, disability, loss of freedom or opportunity, or loss of pleasure) in the absence of a distinct external cause” (“The Goals of Medicine” S9, emphasis added). This definition opens up the concept of malady to include facets beyond the immediate physical condition of the patient. Particularly, the types of “evils” that are identified as constitutive of malady pertain to subjective experiences and not only to objectively observable conditions (For instance, who determines when a death is “untimely”? Or how is “loss of pleasure” measured?). This definition includes suffering (or the risk thereof) as a part of malady—seemingly making malady and suffering (at least in some cases) coextensive with one another, rather than seeing them as distinct albeit potentially related phenomena.

This is a much more robust understanding of malady than the initial characterization offers because it ties together not only the physical manifestation of the malady (the “disease, impairment, injury, or defect”) but also the meaning or significance of this physical manifestation for the patient’s lifestyle or sense of self (e.g.

the loss of freedom, opportunity, pleasure, etc.). Suffering, then, is not just the potential consequence of experiencing a malady, but can be a part of the experience of the malady itself. Thus, in this sense, when providers act to relieve a malady, they may act upon suffering at the same time, as part of the same process. Understanding suffering—or the risk of suffering—as an intimate accompaniment to (or even a part of the experience of) malady has different implications for the practice of medicine than if suffering is understood (a la Veatch) as a separate phenomenon over which providers have no jurisdiction. I would argue that the former is the interpretation of suffering and malady that better reflects the relational nature of personhood, and thus, of autonomy.

### **Suffering and Identity**

In “The Nature of Suffering and the Goals of Medicine,” Eric Cassell argues that although medicine has always theoretically been devoted to the relief of suffering, in actual practice, it has paid little attention to it. Cassell sees this as a product of the persistent influence of Cartesian dualism and medicine’s desire to align itself with the objectivity of science. He argues that for the early practice of medicine, there was utility in conceptually splitting the patient into mind and body. By so doing, medicine could clearly delineate its boundaries, focusing exclusively on the body—the physically observable, measurable, and quantifiable parts that assured its continued alignment with science—while avoiding considerations of medicine’s effect on the “person,” “soul” or “spirit” (which might cause tension between medicine and religion). As a

result of seeing patients in this fragmented way, Cassell argues that medicine has not only ignored or misunderstood patients' suffering, but it has also frequently increased it. Cassell writes, "so long as the mind-body dichotomy is accepted, suffering is either subjective and thus not truly 'real'—not within medicine's domain—or identified exclusively with bodily pain" (Cassell "Nature of Suffering" 640). Cassell's objective is to encourage a more robust understanding of suffering as it relates to the complexity of patient as persons, thus improving the practice of medicine.

From Cassell's perspective, the conflation of pain and suffering does a disservice to patients. He writes that although the two often abide together, the concepts are "phenomenologically distinct" ("Nature of Suffering" 641) and one may arise in the absence of the other. For example, Cassell offers childbirth as a circumstance in which a person may experience a great deal of pain over a significant amount of time and yet not be suffering; similarly, a person may suffer considerably from grief or oppression and yet not be in pain. Thus, for Cassell's purposes, pain is associated with unpleasant or uncomfortable physical sensations of the body, whereas suffering refers to "the state of severe distress associated with events that threaten the intactness of the person" ("Nature of Suffering" 640).

While Cassell may appear to define pain and suffering in terms of the mind/body split he is criticizing, Hillel Braude argues that this is not quite the case. Pain, he argues, is not just the activation of pain receptors or the abnormal signaling of nerves. It does

not belong exclusively to a category of physical things for physicians to examine and act upon. Physicians may inquire about patients' symptoms, ask them to rate their pain on a scale of one to ten, or observe the body to try to identify tissue pathologies that may cause the biological process of pain communication to begin. But these are not simply roundabout methods for wading through the subjective aspects to uncover the true, objective nature of pain as a thing-in-itself. As Braude explains, "Cassell differentiates between the activation of nociceptors, providing the necessary biological basis for the perception of pain, and pain itself, which arises from ascribing meaning to this perception. Pain, like suffering, is both biological and subjective" (Braude 267).

In other words, Cassell understands medicine's relationship to the patient as one that is grounded in concern for the totality of being—including both those aspects traditionally associated with mind or spirit, as well as those traditionally associated with corporeality. He argues that they all "count" in medicine because the parts of the whole cannot be discretely separated out. So while pain may be described as a biological process in which nerves receive and transmit information about specific stimuli—even resulting in spontaneous physical responses to those stimuli—for a conscious person, this is not the whole story. Biological descriptions or observations do not get to the heart of what pain is. As Cassell asserts, "what happens in the person's body—what is perceived in the skin, muscles, joints, intestines, heartbeats, and through the activity of the nervous system—are bodily experiences. As experiences they also



give rise to meaning" (*The Nature of Suffering* 222). Hence, the way a patient feels, interprets, and reports pain is part of what pain *is*.

As such, each experience of pain or suffering will be in some ways unique to the patient, because the meaning of the pain or the suffering depends on the particularities of the patient's life (her identity-forming relationships and commitments, her own personal historical narrative, her way of interpreting the circumstance and assigning it meaning). Because pain or suffering is a subjective and unique experience, it can be isolating. Even if two people share the same occasion for suffering (e.g. parents who have lost a child), they do not experience suffering in the same way because the interpretation of the situation and attribution of meaning depends in large part on how they see themselves in relation to the situation. In this, their identities play a significant role.

For instance, a husband and wife grieving the loss of their child may suffer in unique ways over the same shared experience, depending on how they interpret themselves in relation to one another, the experience, and wider social circumstances in which the experience is embedded. The wife may see the loss in terms of a failure of motherly care, as if greater attentiveness to nurturing her child may have given her the predictive power to ward off disaster. She may criticize herself for not being more attuned to any number of vague symptoms that she retrospectively interprets as clear harbingers of future calamity. She may interpret her past behaviors (such as working,

exercising, taking personal/alone time, or tending her relationship with her partner) as too self-involved, signifying a deficit in the expected level of care and attentiveness necessary to preempt any unforeseen threats to her child. The husband may frame the loss through the lens of his endorsed social role as a provider and protector of the family. To him, the loss of the child may signify the failure to maintain the integrity and cohesiveness of the family as a unit. The loss of the child is not only a personal loss to him, but he may also feel responsible for not preventing his wife's loss of the child as well. Therefore, her grief is an added level of suffering to him, as he could not protect her from the experience of loss that he also is experiencing.

In a similar way, that persons experience pain (or other maladies)—and that the meaning of that pain is constantly being negotiated by a multitude of internal and external factors—gives rise to the possibility of attendant suffering. Persons may sometimes be able to choose when to pay attention to—and when to ignore—certain painful sensations and decide when they are cause for concern. Or, conversely, pain may be constantly at the forefront of one's thoughts and feelings, coloring everything that one does or hopes to do. Persons may choose to (continue to) subject themselves to pain, or may find pain to be tolerable, necessary, or even preferable in some circumstances. In others, it may be excruciating, bewildering, or unbearable. Persons in pain may find their routines, projects, expectations, or moods changed, either temporary or permanently. Changes in the meaning or experience of pain may affect

the duration or intensity of the pain that persons feel, just as changes in the duration or intensity of the pain may affect the meaning or experience of it. Thus, in contrast to Veatch's argument that providers are "experts on the body" (78), and should attend only to that aspect of the patient, deferring all else to a patient's expertise, Cassell argues that, "It is not possible to treat sickness as something that happens solely to the body without thereby risking damage to the person" ("Nature of Suffering" 640).

Cassell argues that when pain is accompanied by suffering, it is because "persons perceive pain as a threat to their continued existence—not merely to their lives, but to their *integrity as persons*" ("Nature of Suffering" 641, emphasis added). In many ways, this seems to complement the Hastings Center's definitions of suffering and malady. Like Cassell, the Hastings Center recognizes a significant temporal element inherent to both malady and suffering. The Hastings Center indicates that suffering is a state in which the circumstances facing a person have become burdensome or oppressive—where both concepts imply significant arduousness in *continuing on* in that condition. This same sentiment can be recognized in the Hastings Center's acknowledgment that malady is not just present suffering, but also the *threat* of future suffering due to actual or anticipated life changes or losses, such as "untimely death, pain, disability, loss of freedom or opportunity, or loss of pleasure" ("The Goals of Medicine" 59). Or, as Cassell puts it, the suffering, "would not exist if the future were not a major concern" ("Nature of Suffering" 641).

The conclusion of Cassell's argument is that, "The relief of suffering and the cure of diseases must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick" ("Nature of Suffering" 639). Patients must be seen as complex and whole persons, and this requires recognition that the concerns of the body are not differentiable from the concerns of the person. So long as physicians continue to ignore or misunderstand their patients' suffering, patients will continue to experience suffering not only as a result of their ailments, but also possibly as a result of treatment; thus, medicine will be in the position of increasing suffering rather than fulfilling its commitment to relieve it.

Building on Cassell's work, I would argue that caring for the whole person requires recognition of the inherent relationality of each patient, and that the current approach to patient autonomy, especially with its emphasis on independence, choice and informed consent, is not compatible with this recognition. As Cassell's work points to, the primary way that suffering compromises autonomy is by threatening identity. Cassell writes,

Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored... Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person.

("Nature of Suffering" 640)

This characterization gets at the heart of the patient experience of suffering. In the midst of illness or pain, it is normal for persons to feel overwhelmed, angry, apathetic, or a host of other emotions. These feelings (coupled with the pain, illness, or diagnostic uncertainty that precipitated them) may be all-encompassing, making regular functioning difficult and leading individuals to feel unprepared and unequipped to meet the demands of their current situations (e.g. work, school, childcare, and medical decision-making may all present difficulties). The longer these circumstances persist, the greater the suffering is likely to be as patients begin to perceive the experience as encompassing not only the entirety of the present moment, but also seemingly expanding to envelop even greater proportions of the person's imagined future. This is also why the diagnosis of a serious, chronic, or terminal illness or a debilitating injury often involves the experience of grief on the part of the patient (and not uncommonly, her loved ones). What feels lost in that moment is not just the experience of health or physical ability or the absence of pain, but the loss of the future that was planned.

When identity is threatened, autonomy becomes much more difficult. Unfortunately, the act of diagnosis itself can sometimes suddenly impose new and heretofore foreign identities on patients (e.g. "cancer patient" or "HIV+"), which can be both disorienting and alienating. In this new identity, persons may feel they no longer know how to relate to themselves—or to others—which may fracture both one's sense of self and one's feelings of security and connectedness to others. Thus, the experience

of illness or injury can have an isolating effect on individuals, while also depleting their coping skills, and undermining their ability to see themselves and their decisions with the same clarity as before. Even experienced medical professionals—when they or a loved one become the patient—may find themselves in a liminal state with regard to autonomy. Although otherwise capable of evaluating choices, making life plans, dealing with surprises or setbacks, and adjusting to deviations of life course, in the face of a major medical event, these capacities may be hampered. Under the duress of pain or illness, or the emotional hardship of suffering (or of witnessing a loved one’s suffering), individuals may find themselves without the resources (knowledge, time, experience, clarity, etc.) to act completely autonomously—at least according to conventional metrics. Yet, precisely at these moments, patients often must make life-altering decisions that may affect their own health (or the health and life of a loved one) for years to come.

This is an enormous burden that is placed on patients at a time when their general autonomy competencies may be inadequate or overtaxed. What’s more, as discussed in the previous chapter, many people lack the health literacy and medical familiarity to operate effectively as autonomous agents within the healthcare system, even when they are well. As such, when calamity strikes, they often only have a little practice making smaller, lower-stakes decisions to draw on. Relationships of trust are needed immediately—including a patient’s trust in herself and her competency to act

effectively in these situations, as well as trust between the patient and the providers upon whom she now depends—but these relationships take time to develop. Instead, patients may feel insecure and haphazardly thrown together with their providers, who feel like strangers bearing bad news.

Unfortunately, in these circumstances, contemporary healthcare practices, with their intense focus on respecting patient autonomy, may (inadvertently) only further undermine it. Providers recognize that patients need to be responsible for their healthcare decisions because they are the ones who must live with the consequences that their choices produce. So most providers work diligently to engage and inform patients, and ensure that the decision is left entirely up to the patient. From the patient's perspective, however, these efforts may not be received as intended. Especially in the context of pain, anxiety, uncertainty, and heightened vulnerability, patients often report feeling rushed, overwhelmed, and assaulted when a decision about treatment or research participation is required. Instead of informed and confident, suffering patients may feel that they are being sent in blind and alone into a field littered with landmines. Choosing a desirable path in this scenario does not feel like a matter of autonomy, but rather a matter of luck.

While it is true that medicine provides no guarantees, for many ailments, the healthcare that is available today is simply too good to leave patients feeling like their health has been left up to chance. It is not unrealistic to claim, as Veatch does, that

people can have healthcare experiences that match their values, meet their needs, and in most cases, give them the opportunity to continue on with life plans more-or-less of their own choosing. But hyper-vigilance about patient autonomy (in the traditional, individualistic sense), choice, and informed consent is not the most desirable way to get there. Instead of focusing on individual patients in discrete circumstances of choice, a more holistic approach is required—one that sees patients in the context of their lives and relationships, and which builds trust and health competence over time. One place to start is with greater support for welcoming and involving patients' providers and loved ones into the patient's clinical experience—to the degree to which the patient feels comfortable—without undue worry that such connections threaten autonomy.<sup>38</sup> As Nistelrooij et al. have argued, "In some cases... the patient is neither capable nor willing to retreat to his or her individual autonomy, but needs and wants to involve others in the decision-making process. In these cases, others are not considered as a threat to one's individual rights, but rather as indispensable support for asserting one's rights" (643). In the next chapter, I will return to my critique of Veatch's account to demonstrate how a relational approach to autonomy, which recognizes and welcomes a patients'

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<sup>38</sup> This inclusion does not mean that all relationships patients have are positive or that coercive ones are not harmful. To the contrary, damaging relationships do need to be taken into account, as these also contribute to a patient's identity, goals of care, etc. Certainly no one should be *forced* to consult with family or friends or others, as this would be an oppressive burden for some. And we should certainly be on the lookout for coercive relationships that are overburdening patients in ways that patients do not want. This is where other relations of support, such as from the community, clergy, social workers, etc., become vitally important – to step in and buffer patients from connections that truly are undermining autonomy.



providers and personal support network into the decision-making context, better serves the needs of patients and helps to alleviate suffering.

## CHAPTER 9: PATIENTS IN RELATION

As I have argued, illness, serious injury, and suffering can radically affect identity and undermine autonomy—especially if autonomy is conceived in the traditional sense. Thus, the early experiences of patients who are suffering from serious injuries or illnesses may not reflect total autonomy as traditionally conceived. Patients in these circumstances may need to rely on others—medical experts, family members, friends, or spiritual support—to look out for their interests, help them avoid treatments and circumstances that increase suffering, and help them decide what discomforts may be necessary given their understanding of themselves and their life goals. But if autonomy is understood relationally, then the others upon which a person depends—especially in times of suffering—can act as the stewards of identity, helping to restore a fragmented self and preserve patient autonomy during periods of increased vulnerability and dependency. Having strong familial or social support distributes the burdens of the healthcare encounter (e.g. physical navigation; communication with the multitude of providers and staff; insurance and financial considerations; coordinating time away from school or work, etc.) and helps make illness more manageable.

In best-case scenario, a person who is suffering can rely on robust connections with others to preserve her identity and autonomy at times when it may feel under siege. Friends or family members may band together with the patient and her providers to devise a course of action that is in keeping with the patient's identity, experiences, and life goals. The patient may depend on these loved ones to help her decide, or to take the reins for a while during times of considerable pain or distress. In such joint or surrogate decision-making, Lisa Rasmussen posits that the surrogate acts as "the historian of what the patient would want were he competent to decide" (389). This imagery calls to mind Westlund's assertion that autonomy requires a sort of social accountability. Building from that, I would argue that a primary benefit of having given a genuine account of ourselves to others through our enduring relationships is that during times of suffering, we may then depend upon those "historians" to give an account of ourselves back to us, reminding us of our identities and relations at times when we may otherwise feel lost and disconnected.

From this perspective, a patient relies on loved ones' enduring understanding of the patient over her life to guide their decisional considerations, and she trusts (or at least hopes) that they will act with fidelity to her character and values. This trust and solidarity disperses the burdens of her current situation, reducing the suffering of the patient to a significant degree. As Cassell puts it, "Recovery from suffering often involves help, as though people who have lost parts of themselves can be sustained by

the personhood of others until their own recovers” (Cassell, “Nature of Suffering” 644). The loved ones, as integral elements of the patient’s identity, and keepers and protectors of that identity while it is in limbo, play an essential role in the clinical context. They work with the patient “behind the scenes,” in the time between patient-provider encounters. They have time and subtlety on their sides; they can wait, and coax, and grieve with patients, sharing in the experience in a way that busy, overburdened providers often cannot. In this way, they provide indispensable support not only to patients but also to providers. If these types of connections are absent, denied, or cast aside during the experience of illness or injury (and especially during times when “punctate decision-making” is required), then there is a risk that the malady—or even the treatment itself—may cause profound damage to the patient’s sense of self, which can further fragment her identity, diminish her autonomy, and frustrate or undermine her attempts to regain an integrated sense of self and to live a life that she would consider satisfactory.

But it is not only one’s relationships with friends and loved ones that are important to protecting or restoring patient autonomy during times of illness, injury, and suffering. Contrary to Veatch, who seeks to minimize provider-involvement in patient care decisions, Cassell argues that, “Inevitably, and necessarily, the doctor is part of the therapy. I do not mean simply that the doctor administers the treatment, but rather that the person who is the doctor is a central part of therapeutic medicine” (*The*

*Nature of Suffering* 111-112). In this final chapter, I am arguing that loved ones and other social support are essential to protecting patient identity, and thus autonomy. The way that a patient understands herself in relation to others is a critical part of identity, and therefore those upon whom the patient depends most to help maintain the integrity of that identity during times of distress should have a recognized place in the decision-making process. I also argue that a robust provider-patient relationship is essential to autonomy. In contrast to Veatch, who criticizes providers for being overly involved in patient decisions, I argue that patients want providers to give input, provide support, and even share their own values and judgements. When patients feel least secure, confident, and autonomous (as they typically do during difficult health experiences), they often need and want to depend on their providers to be trustworthy guides in navigating the complexities of disease, wellness, and healthcare. Hence, if providers are going to be effective in the goals of relieving suffering and restoring health, they must approach patient autonomy relationally, understanding the patient as a complex and whole person whose relations to others—including to the provider—cannot, and should not, be cast aside in the interest of promoting the conventional individualistic and choice-oriented conception of autonomy.

### **Veatch's Extreme Autonomy vs. Relationality**

Veatch's approach to patient autonomy requires a level of independence, self-confidence, assertiveness, and health literacy that is difficult to come by amongst most

(non-medical) laypersons. Often in his text, it feels like Veatch is fostering active mistrust of providers' who attempt to respond to more patient needs than he feels they are qualified to address. For instance, he challenges that,

[A]sking your doctor is nothing more than asking the expert on the body for his or her religious, philosophical, or cultural preferences about taking a very small risk of a serious problem in order to have a good chance of relieving a relatively minor one. Medical school can't teach doctors the right answer to that kind of question. (Veatch 78)

Veatch's point is that determinations of medical benefit or suitability involve value judgments that it is inappropriate for medical professionals to make on behalf of patients. In one sense, this is not an objectionable claim: it is obviously inappropriate for providers to *impose* their values upon patients. But in another sense, just because a question of care involves more than considerations of the physical body—as if care of the physical body can be separated from the life of the person whose body it is—does not mean that it is inappropriate for providers to offer patients whatever wisdom they have gained on the subject from their training and experience. In fact, as Cassell has argued, providers are obligated *not* to treat patients as though they are simply bodies under observation; instead they can and must attend to the whole person, which may include having a conversation about values if this will benefit the patient.

Veatch argues that medical recommendations, standards, and guidelines are born out of a professional bias that disproportionately values medical wellbeing. He asserts that it is the nature of medical practice that, “physicians will want us to expend more of our limited resources of time, energy, and money on the medical sphere than makes sense taking into account the impacts on other spheres of life (and, therefore, on total wellbeing)” (Veatch 36-37). In other words, medical professionals have an inescapable bias in favor of health (and the practices and interventions that they feel best promote or restore health), and this bias colors their clinical recommendations. This causes them to give inappropriate and sometimes unrealistic medical advice that oversteps the bounds of medical “fact” and extends into the realm of value judgments. In Veatch’s account, the most common and detrimental mistake that providers are guilty of making (at least with regard to autonomy, if not with regard to clinical outcomes) is presuming to know what is “good” or “beneficial” for their patients. This, Veatch argues, is a determination that providers are not qualified to make. Instead, providers should “concentrate exclusively on the medical” (37) and leave determinations of what is good or beneficial up to the patients. From his perspective, providers simply cannot know what is in their patients’ best interests, and therefore it must be left to the patient to decide. This approach links providers (and the whole of medical practice) with physical bodies, separating out persons and values as a distinct concern. In so doing, Veatch’s approach actually undermines patient autonomy by

removing the “patient” from her body. His arguments put him in the peculiar situation of trying to promote autonomy and empowerment while limiting providers’ ability to interact with and treat the patient as a whole person.

In the previous chapter, I described Veatch’s position that patients should have the freedom to make any medical choice that they desire, constrained only by legal limits, not medical standards (“the tyranny of experts” 256). This perspective takes the individual patient to be the center around which everything else in the clinical encounter revolves. There is no discussion in Veatch’s work about the influence of others (e.g. friends, loved ones) on patient decision-making, or about the influence of patients’ choices on others. But as Rasmussen explains,

[T]he values of the patient can conflict with others who are affected by the decision... healthcare providers and family members may have different priorities but may be required to suffer the consequences of the patient’s wish...

[T]he choices that individuals make often require resources of time, energy, and money from others. A clinical ethics decision is almost never only about an individual and her wishes. (389-390)

Since patients are persons in relation to others, they will have an impact on those with whom they are connected. As such, individual preference is very unlikely to be the only constraint on patient choice.



Furthermore, in the interest of autonomy as choice, Veatch argues that patients should be permitted to make any type of choice they like, including very poor choices and choices that harm them (e.g. taking contraindicated medications together, having a surgery that is unlikely to result in medical benefit, etc.), and that providers must not interfere with this in the interest of respecting patients' rights. While I certainly am not advocating a resurgence of paternalism, I would argue that a provider's fiduciary responsibility toward her patients will sometimes require her to be explicit about values—particularly the values or goals inherent to the practice of medicine—which cannot, or should not, permit some types of patient choices. Nearly all patients value health and desire to maintain or regain it, so when a patient expresses a preference or desire to choose a course of action that will have a very poor or unintended outcome, a frank discussion between provider and patient about values and goals is warranted.

As Richman and Budson argue, health is a concept that is defined in relation to goals and expectations. On their account, a key feature of health is having “the ability to do the things we reasonably want to do” (Richman 453). Consistent with Veatch, they claim that what counts as “health” or being “healthy” depends to a great extent on the characteristics of an individual, and somewhat less on the pre-defined standards and thresholds that characterize the science of medicine. To illustrate this point, they call attention to the difference between “*the health of an individual qua organism* and *the health of an individual qua person*” (Richman and Budson 343, original emphasis). This

distinction recognizes that although what counts as “health” for an organism may essentially be boiled down to the ability to achieve basic biological goals (e.g. growth, reproduction, homeostasis, etc.), what counts as health for a person is invariably more complex. For persons, health may entail the ability to pursue a panoply of goals, many of which will be in addition to—and in some cases, even in lieu of—the basic biological goals of species-typical functioning.

This is not to say that individuals are not highly motivated by the organism-level components of health such as survival, procreation, or general physical equilibrium. On the contrary, for most people, functions of this sort maintain a very high level of priority, in large part because deficits in these areas can also hamper the achievement of other broader goals. For example, many people consider the physical ability to produce progeny to be an emblematic component of health; therefore, obstacles to this goal (such as infertility) may detrimentally impact an individual’s experience of her health, as well as affect a variety of her other personal, religious, financial, and social goals. And, in general, there is often substantial congruity between the goals of the individual as both an organism and as a person. However, being able to deliberate about what value the pursuit of other goals may add to an individual’s life (especially when they are not strictly congruous with the basic, species-level goals) and about what sacrifices, trade-offs, and reprioritizations may be needed in order to facilitate the achievement of those goals, is also an essential element of being a person and of having autonomy. As such, a

person may choose to endorse a degree or expression of “health” that is not consistent with the highest priorities of the medical profession, but which strikes a more satisfying balance between her provider’s recommendations and the type or level of bodily functioning she finds adequate to continue pursuing her other goals.

Take, for instance, two running enthusiasts who present with the same sports-related injury. Although neither is a professional athlete, their commitment to the hobby over several decades has led them both to develop the same painful and mildly debilitating condition. Both runners are subsequently told by their physicians that they should retire immediately from the sport or else risk chronic pain, further damage, and even permanent disability. Yet while the diagnosis and prognosis are identical for both patients, the impact of this experience manifests differently for each, owing to the variations in their preferences and goals. One runner easily transitions to a lower impact activity that she finds comparably enjoyable, thus decreasing her risk of progression, and, in her estimation, improving her health through the reduction of pain and the prolongation of normal function. The other patient, an avid member of her local running club who takes great pride in her identity as a runner, experiences an immediate decline in her perceived level of health. For her, the recommendation of her physician represents a greater burden than it does for the first patient. Unwilling to give up the benefits of camaraderie, pride, and enjoyment that come from her affiliation with the sport and the other members of the club, she decides not to retire at the time,

instead accepting the risk of further injury in order to continue running until which time as the injury renders her unable to carry on.

Part of what is distressing about the experience of illness or injury is the way that it draws these basic organism-level biological processes to the foreground. As Stan van Hooft articulates, “When malady strikes, this preconscious harmony in our being is altered and our bodily existence becomes a centre of attention and concern” (Hooft 127). The experience of suffering robs individuals of the feeling of security that often accompanies health, and jolts them into acute awareness of the fragility and limitations of their biological condition. If the suffering is severe or ongoing, it threatens to suspend or terminate the pursuit of their other goals. These feelings of loss and of being lost—especially the loss of security, loss of control, or loss of the future one had imagined for oneself—can have a disorienting and sometimes profoundly damaging effect on a person’s sense of self.<sup>39</sup>

Understanding patients’ goals is key to a successful clinical encounter; however, when patients’ goals are unrealistic, unreasonable, or based on misinformation, it is a provider’s duty to help patients understand the limitations of their current situation and what options and outcomes are medically possible. This is where this approach parts ways with Veatch. Richman’s idea of “goal therapy” begins with deliberate, candid communication between provider and patient about each party’s expectations

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<sup>39</sup> Elisabeth Kübler-Ross’s Five Stages of Grief model speaks simply and eloquently to this very common—and very human—way of processing such anguish.

for the clinical encounter. For the provider, this involves outlining clinical goals (e.g. restoring function, inoculating against contagious illnesses, or providing palliative rather than curative care, etc.) and being straightforward about what changes or outcomes patients may expect as a result. It also involves taking the time to understand the patient's goals and expectations (e.g. being well enough to return to work or school, being able to care for dependents, competing in an athletic event, etc.), as well as addressing any misinformation, misunderstanding, or information gaps that may cause the patient to have unrealistic fears or expectations.

Richman argues that it is especially important for providers to take the time to engage in such dialogue when a patient's choices seem contrary to what is expected or perceived to be reasonable. Contrary to the currently widespread belief that such inquiry into patients' motivations and values (as they pertain to treatment choices) is inappropriate, paternalistic, or coercive, Richman argues that it is an essential part of protecting patient autonomy. Calling to mind Westlund's relational approach to autonomy, which requires an openness to dialogue and a willingness to provide an account of oneself to others in response to legitimate inquiries or challenges, we can see how this mutual accountability can enhance the provider-patient relationship and protect autonomy. Patients cannot really provide fully informed consent for a care plan unless they understand the intention behind the provider's recommendations. Similarly, providers cannot provide treatment recommendations that are truly in the

patients' best interests unless they have some idea of how the patient defines or prioritizes those interests. Thus when providers and patients make their goals transparent and understandable to one another, it can help avoid confusion, change misguided beliefs, lead to better treatment recommendations, and increase patient satisfaction and compliance.

When Veatch speaks about allowing patients to make their own choices and value judgments, it must be realized that Veatch, speaking from his experience as a pharmacist and ethicist, is better informed and more familiar with the complexity of healthcare decision-making than many patients are. This is evident in the way he poses the earlier problem of values, because when he describes a provider's inability to advise a patient about the tradeoffs between "very small risk," "a serious problem," and "a relatively minor one," he makes a series of qualitative, subjective assessments (e.g. "small," "serious," "relatively minor") that are all informed by his medical background. These are assessments that laypersons are typically less informed to make, and this is a reason in itself for them to seek provider input. It is precisely because the provider is biased by her medical experience and the esteem she has for the value of her profession that it is valuable to seek her advice in the first place.

Many laypersons don't know, prior to a discussion with their providers, whether they are talking about large or small risks. Even after lengthy discussion of risks and tradeoffs, they may misunderstand the degree of risk, the probability of a certain

adverse event, or even how providers would define a “successful” outcome and how that would differ from a patient’s definition of success (e.g. “5 years event-free survival” is a very successful outcome in cancer treatment, but this is neither the language nor the measure that patients would typically use to define success). Most patients have no basis for making determinations of that sort. They don’t know which of their current medications might interact badly with a new one. They don’t know whether they are more likely to experience short or long-term side effects due to an underlying health condition. Asking their doctors is not like consulting a Magic 8 Ball for help making decisions. Asking their doctors is a way to receive specific, interpreted and personalized medical information that can help them understand what level of risk a new drug or procedure poses and determine whether they find that risk-benefit profile tolerable.

Assuredly, patients by and large do not want their providers to make (non-emergency) decisions for them in an authoritarian manner. They do not want to be left in the dark about their health and healthcare. However, especially when it comes to serious illness or injury, patients and families often report feeling more in control when providers take the time to explain why they think a particular option is a good or better fit for a patient, even if this may be construed as influencing the decision. Patients and families generally do not want to be left entirely to their own devices; they want to understand why an option might be the best option and have the opportunity to dissent

or concur, but they typically do not want to try to make these decisions themselves in a value-free vacuum.

Veatch's claims about the new medicine rely heavily on a level of individual autonomy in medical decision-making that would be difficult to achieve for most people. The question of whether most people want to assume—or are capable of assuming—this level of responsibility for their health and healthcare is not given considered discussion. The desirability of the patient's role in the new medicine is taken as given. In reality, many people *would* benefit from a redistribution of power in the provider-patient relationship. Unfortunately, there continue to be providers who still blatantly espouse paternalism and expect to be treated as authorities on health to whose judgment patients should unquestioningly defer. There are also providers who either knowingly or unwittingly perpetuate problematic stereotypes, act upon assumptions about patients, or impose their own values—all of which can undercut autonomy and harm the therapeutic relationship. Because of these and similar problems, some patients would likely find a new, elevated status like Veatch proposes to be valuable, empowering, and beneficial. But it is also likely that many of the people who embrace this elevated status of the patient in the new medicine would be people who already experience a great degree of autonomy afforded to them by privilege and membership in groups already treated with a great deal of respect. By contrast, there are also likely to be many people who feel profoundly uncomfortable or overwhelmed by the patient's



status in Veatch's new medicine because it presumes a level of assertiveness and medical literacy amongst patients that is not currently universal. Veatch presumes a static, threshold level of patient autonomy across the board, without consideration for the fact that autonomy is an exercise concept and this capacity must be built over time. In essence, he fails to realize that while swimming may be good exercise, it is usually best not to throw someone who has scarcely done it before directly into the deep end.

Veatch's approach also does not allow for the possibility that some people simply may not want a partnership with their healthcare providers, much less to be the "managing partner" in the arrangement. There genuinely are persons who are neither accustomed to, nor interested in, taking an active role in such encounters. Instead, they prefer to take on the role of follower rather than leader, and they may be uncomfortable with the idea that their decisions should have such significant bearing on the course of treatment. There may be many reasons that they simply are not comfortable taking on such responsibility. For instance, they may be worried about a poor outcome from choosing badly, or may be disinterested in "doing the provider's job" for her. They may be private persons who prefer not to divulge so much information to strangers, or they may feel overwhelmed and incapable of making an informed decision. For them, a primary benefit of seeking out a medical expert is the ability to delegate difficult decision-making to someone trustworthy who has, through extensive training, gained greater relevant experience in that area. For others, the amount of information and other

variables that must be taken into consideration when deciding amongst available alternatives is staggering. It is likely that at least some people would take this new responsibility so seriously that they would begin to suffer from analysis paralysis. Still others might treat healthcare decision-making with such nonchalance that they end up worse off than they might have been under the old model of benevolent paternalism.

Veatch claims, “It is unrealistic to expect experts in any one component (sphere) to be able to speak knowledgeably about well-being in the other components... Therefore, it makes no sense to expect them to devise proposed interventions that will promote the total well-being of the individual” (Veatch 100). But few, if any, people expect doctors (or persons of any sort) to have the level of professional expertise, personal experience, emotional intelligence, and philosophical wisdom to be able to offer infallible recommendations customized to the holistic and particular needs of each patient. To expect this would be grossly unreasonable. Instead, what patients generally want is not a hands-off, value-free presentation of the options—since this would likely come across as cold, impersonal, and a bit tone-deaf, especially given the gravity of many medical situations—but rather a reasonable interpretation of the options from the perspective of another who, among the other varying strengths and weaknesses of being a complex human person, also happens to have specialized medical expertise. When patients ask, especially under particularly weighty circumstances, what their provider recommends, more often than not, they are cognizant of the limitations of the

advice being offered. They are actually seeking that “something added” that Veatch criticizes.

Veatch repeatedly claims that medical professionals cannot know what their patients’ best interests are or advise them without bias about which medical options to pursue. But I would argue, most patients do not really want unbiased, uninterpreted medical information. This is the reason that many patients seek out the advice and care of their physicians instead of relying on their own capacity to discover and apply medical information for themselves. The opinions of other laypersons or the information provided on medical websites can only take a patient so far, and may actually serve to further confuse the issue in some cases. And in situations where providers do take this “hands off” and “value-free” approach to care that Veatch recommends, presenting options neutrally or with statistics, facts, and figures, without reference to patients’ values (and fears!), many patients lose trust and confidence in their providers and instead seek “alternative” therapies. Hence, it is more likely that a patient will be dissatisfied with her provider, hospital, or health experience if the clinical encounter feels detached, impersonal, and unbiased. It is more often in those circumstances that patients report being unaware of what to expect, not understanding the implications of their choices, and not receiving quality healthcare. As White and Zimbleman counter, “We believe that even if clinicians cannot know patients’ *best*

interests, they can acquire sufficient knowledge of patients' *reasonable* interests successfully to promote them in the clinical context" (483).

During difficult clinical encounters, it is not uncommon for patients or loved ones pose the question, "If it were you, Doctor, instead of me, what would you do?" In reality, despite the provider's experience and medical expertise, if she was in the same situation as the patient (e.g. having just received a difficult diagnosis, or having just found out that a loved one has suffered a serious injury), she would likely feel exactly the same—unsure and overwhelmed. But what questions like this are really getting at is, "if you were in my situation, and you knew what you know, but you also valued what I value, and feared what I fear, what would I do?" Of course, it is not possible for a provider to put herself fully and infallibly in the patient's shoes, but this does not mean she is exculpated for not providing her best response to a similar question that she can answer, namely: "given your medical expertise and what you know about me, and having as similar of underlying fundamental values as any two people can be assumed to have, what do you think I should do?" An honest and empathetic response to such a plea is unlikely to undermine patient autonomy by coercively influencing the patient. Rather, it is likely to offer valuable insight that can strengthen patients' abilities to come to a decision that reflects their own identity, preferences, and understanding.

Of course there are ways that this approach can—and has—let down patients. Doctors may be too busy for an in-depth discussion. They may have preconceived

notions about what patients' interests are. They may be more conservative or more radical in their approaches to medicine than patients may prefer or be comfortable with. All of these are reasons why Veatch argues that provider judgments on what serves the best interests of patients ought not be offered, preferring instead that patients decide for themselves without the influence of their provider's background opinions. But this is not a tenable solution. Just because a provider can be wrong about what is in a patient's best interest does not mean that provider judgments are—across the board—unjust or unhelpful and should therefore be dismissed. Or as White and Zimbelmen explain,

[T]o function *at all*, any practical discipline – and medicine is no exception – must act *as if some* goods are worth pursuing, *as if some* goods advance *some discrete, discernible, and legitimate* interests of clients. For a practical discipline, then, the relevant question is not 'Which good must *everyone* pursue?' but rather, 'Given our particular (professional, community, or individual) values, which goals ought *we* reasonably to pursue?' And such queries readily yield valuable knowledge upon which actions can be based. (483, original emphasis)

Hence, value neutrality is not realistic, nor even necessary. Furthermore, as many philosophers of science have argued, there is not a discrete way to separate out subjective "values" from objective "facts." Value judgments are embedded in every aspect of science and medicine. They creep in at the very beginning of inquiry and play a supporting role throughout the entire endeavor. It is not helpful to pretend that facts

can be isolated from values in order to give patients a “clean slate” of objective, medically pertinent information from which they can choose the best course of action. Rather, what we need is greater transparency about values and limitations, better education about the processes that pre-determine the availability and safety of the current options, and stronger, more clear communication between not only providers and patients, but also patients and insurers.

## CONCLUSION AND FUTURE DIRECTIONS

In the first part of this project, I investigated the concept of autonomy, examining its philosophical and historical origins and exploring the ways that concept has evolved over time through its adoption and use in a variety of disciplines and social avenues. I then critiqued the dominant conception of personal autonomy that has become ubiquitous in Western culture, arguing that it is individualistic, exclusionary, and not representative of how most persons experience themselves in the world. Instead, I argued for a relational approach to autonomy, which recognizes the essential ways our connections to others and the outside world shape our identities, the way we act, and the type of future we imagine and pursue for ourselves.

In the second part of this project, I argued that the dominant conception of autonomy that is operational in bioethics and medical practice today is consistent with the individualistic version of autonomy that I critiqued in the first part. This association has had several undesirable consequences, including distorting the provider-patient relationship, overemphasizing choice and informed consent, and undermining relationality. The effect of this approach is that when patients encounter the medical establishment amidst the overwhelming experiences of illness and injury, they may find

their suffering increased, rather than alleviated. Instead, I have proposed that medicine and bioethics adopt a more relational conception of personal autonomy, understanding the ways that providers and loved ones can work together to restore and protect patient identity and autonomy, and reduce suffering.

My discussion in the second part has primarily focused on the experiences of patients as they encounter the healthcare system in the immediate aftermath of an acute health crisis such as illness or injury. However, one aspect of healthcare that holds significant interest for me is medicine's increasing ability to predict or foresee future illnesses, and the effects this may have on patient identity and autonomy. For instance, Timmermans and Buchbinder have discussed how newborn screening—especially screening for conditions for which there is no cure or standard treatment—creates the phenomenon of “patients in waiting.” These individuals are (or at least appear) healthy, yet they are marked by some genetic portent of future illness. Unfortunately, uncertainty over how to attend to persons in this liminal state is compounded by a lack of data.

As Timmermans and Buchbinder point out, the ubiquity of newborn screening is a relatively new development. Previously, diagnosis depended on the presentation of symptoms; thus, until lately, newborns with predispositions to illness or late-onset disorders were not known or considered to be unwell until symptoms began. For affected patients, there was simply no reliable way to detect these genetic harbingers of



future disease. As a result, the health events of their early years were not interpreted in the context of potential or inevitable disease. However, now that predictions of future disease states can be made through routine testing at or before birth (and this has largely become standard of care), it is now possible to advise parents about their child's risk of disease well in advance of its onset. But, due to the newness of this ability, there isn't a significant repertoire of early data to analyze in the effort to distinguish normalcy from pathology in the developments of children thus identified. This data is only now being collected. This puts parents in a peculiar situation of caring for and anticipating the health needs of a "sick" child who is currently well.

A related and interesting effect of advances in predictive and screening technology (e.g. genetic testing, mammography, colonoscopy, etc.) is that providers are not only better able to detect diseases at earlier stages of development when they are more likely to be effectively treated or cured, but they are now also able to identify potential concerns even in their "pre-disease" state. For example, many patients are now being told that they are "prediabetic" or "prehypertensive," that they are in "pre-heart failure," or that some cells are "precancerous." In these circumstances, a finding may not yet meet the diagnostic parameters for disease and may not even cause the patient any symptoms. In the past, most of these preconditions would not have been detectable at all and may have had no discernable effect on the patient—at least not for several years, and possibly never. But because of public health initiatives to shift greater

attention and resources towards preventative care, combined with the fact that more individuals now have better access to healthcare than in the past, providers are increasingly able to screen for and recognize abnormalities as potential precursors to disease.

Similar to infant testing, this puts patients in a curious position. A patient with prediabetes does not have diabetes. Rather, she is at risk of developing diabetes. But the way that this status is communicated to the patient is often as though this precondition is its own unique disease. In fact, on its webpage, the CDC advises patients to talk to their providers about routine monitoring for prediabetes if they believe they are at risk. This way of presenting the information makes “being at risk of a disease” a health problem in itself, and further regresses to the point of essentially telling patients to watch out for being at risk of being at risk. This is a confusing message that puts patients in the odd predicament of seeking care for and trying to live with a disease that has not yet arrived, and this early adoption of the patient role may have interesting implications for identity.

Cancer survivors and patients with genetic predispositions to diseases that have not yet manifested also find themselves caught in the same paradox: they are “neither sick nor healthy” (Hauken et al.). Both may be clinically well in the present moment, but they do not experience their health in the same way that others do. They do not have the luxury of being able to take it for granted. For both, the duration of continued

wellness is unknown and fraught with contingencies. For them, maintaining health requires continuous surveillance in which they scrutinize themselves for signs or symptoms of a disease that may or may not ever come.

For cancer survivors, their current identification as “healthy” may be undermined by anxiety about recurrence (relapse) of their former disease, the emergence or continuation of late effects from their earlier treatments, or the appearance of secondary cancer(s) that may be refractory to treatment. These survivors are intimately familiar with the “patient” identity and know firsthand how interminable pain and suffering may be, sometimes persisting long after clinical convalescence. They and their families have learned that recovery of the “whole person” is not always simultaneous with the restoration of physical health, and even then, remission may be fleeting.

Similarly, for individuals with certain genetic predispositions, such as those with genetic markers for Huntington’s Disease, it is not a matter of *if* they will develop disease, but *when*. While for providers the availability of genetic testing technology now provides the opportunity to obtain the information requisite to effectively diagnose a terminal illness well before a patient even becomes sick, this technology simultaneously puts patients in the unusual predicament of having the opportunity to decide whether or not to learn whether they have received a genetic “death sentence,” perhaps years or even decades in advance of when they can expect the first symptoms to manifest. For

others, such as those with the so-called “breast cancer genes,” genetic testing does not reveal certainties but only vague probabilities—“if” and “when” remain open questions. Hence, for those in the former group, their future “patient status” is all but guaranteed. For those in the latter, they have good reason to fear that their current health is fleeting, but it is often not something they can be sure of. For both, suffering may result from trying to reconcile a current healthy identity, and the life plan one had designed around it, with the possible or impending loss of both this identity and its seemingly “open” future.

Even for patients whose preventative or predictive screenings find diagnosable disease present, the implications of a positive result are not immediately clear. For example, according to the CDC, prostate cancer is the second most common form of cancer found in men, with most cases detected in men aged 65 and older (“Prostate Cancer”). This cancer is usually localized to the affected organ at time of diagnosis, and in the majority cases, it is slow-growing, taking 15 years or more to metastasize or cause symptoms. This means that although a high percentage of men will eventually develop prostate cancer, even without screening, most of them are likely to live into their 80s without the disease ever causing noticeable health effects. As a consequence, the CDC explicitly instructs men that, “Finding and treating prostate cancer before symptoms occur may not improve your health or help you live longer” (CDC “Prostate Cancer”). And, in fact, a significant proportion of men who have undergone treatment for

prostate cancer have “treatment regret,” reporting that if they had better understood the consequences of the treatment options (such as different types of surgery and radiation therapy, hormone therapy, and investigational treatments), they would have elected no treatment or “active surveillance” only instead of active treatment of any kind (Shaverdian).

Prostate cancer is an interesting case for consideration because it is one of very few serious and deadly diseases where doing nothing may be an ideal treatment approach. It is also interesting because the disease and its treatment are tied very strongly to personal identity through the prostate’s association with masculinity. In Alex Broom’s qualitative study of men’s perceptions of their treatment experience, he discusses the stereotypical male approach to healthcare, where “Statements like ‘I haven’t been to the doctor in 25 years’ reinforce the ‘appropriateness’ of denial or complacency, constructing avoidance as a quality to be admired and the unexamined body as the strong body” (Broom 80-81). He then examines the effects of diagnosis and treatment on men’s perceptions of their own performance of masculinity. For instance, he describes how the conduct of a digital exam during a prostate cancer screening or the perceived invasiveness of prostatectomy surgery make many men feel uncomfortable or humiliated due to prevailing cultural stereotypes and taboos surrounding manliness, (hetero)sexuality, sexual vigor, and the bodily areas that must be accessed in order to perform these procedures. Even after therapy, Broom reports that some men continue to

feel anxiety or shame surrounding their own (masculine) identity owing to the side effects of treatment (which may include urinary incontinence, bowel disorders, and erectile dysfunction) or the loss of feeling physically “complete” or “potent” as a man.

Broom’s study does a beautiful job of describing how the diagnosis and treatment of prostate cancer impacts men’s perceptions of themselves and their masculinity, especially as it relates to the integrity and function of their bodies, and the personal meaning they ascribe to feeling intact and sexually vigorous. But what Broom glosses over in his discussion is the way that men’s relationships with others factor into their treatment decisions and how they think and (don’t) talk about their disease. Many of the men quoted in Broom’s study talk about their illness in relation to others, and it is clear that these relationships have a significant impact on their own perceptions of themselves not only as men, but as fathers, husbands, brothers, and friends. For instance, when asked about men’s healthcare practices (like decisions to have screenings and checkups), one man replied,

I guess it depends what sort of a wife you’ve got [laughs]. If you’ve got a wife who takes some interest in your health, you get pushed into it. But, for a single guy who has to make these decisions on his own, unless there is something drastically wrong, he’s probably not going to do anything. (Broom 79)

This response demonstrates the way that perceiving oneself as a person in relation to others can affect one’s judgment about the value of self-care and heighten one’s sense

of responsibility and accountability to engage in care practices not only for the benefit to oneself, but also for the benefit of one's relationships. Particularly intimate relationships (such as between partners or spouses) can offer security and support during vulnerability, which can foster a greater willingness to face challenging circumstances (like cancer treatment) more assertively.

The types of relationships that one has also cause different aspects of identity of character to come to the fore in different contexts. As one man confessed,

I didn't tell anyone that I had prostate cancer, I haven't told any of my friends, because they don't understand; you tell people you've got any type of cancer, and they think you're dead and buried—it could affect your relationships with people. So my friends and close friends don't know that I have prostate cancer. I was also reluctant to tell any of my family; I've got five children. (Broom 84)

For this man, being perceived as strong and healthy by his friends and children was not simply a matter of pride. Rather, he feared the possible change or loss of his relationships because of the anxiety and misunderstanding others might experience concerning his disease. To spare others' discomfort, he chose to keep his experiences as a cancer patient hidden so that it did not compromise his relationships in circumstances where he felt this aspect of his identity had no bearing.

Similarly, another man voiced his sense of loss concerning the change in his relationship with his wife after treatment, and his fears about the stability and longevity of his marriage owing to his cancer treatment, saying,

When we had the kids, we were busy and sexual attraction waned, but when I was 55, my boys were off at uni and we had some time to ourselves, and we had matured sexually, and it had become an important part of our lives. Now, we've never got that back [after the radical prostatectomy]... I've seen marriages break up from guys who have had a radical and never got back on deck with their potency... I've seen it create difficulties in quite a few marriages... (Broom 86)

These types of testimony demonstrate the impacts of illness or treatment on individuals and those with whom they are connected, which may persist long after the health threat has resolved. They also point to the importance, as I have discussed in this project, of a robust provider-patient relationship—one which is respectful of relationality, and which promotes frank and ongoing discussions between providers, patients, and their loved ones about the patient's goals, the provider's goals, and the realistic probability of achieving desired outcomes.

But what the case of prostate cancer screening and treatment also brings up is preventative and predictive technology's role in creating "sick" or "potentially sick" identities where they may not have otherwise existed, and the utility of treating patients for illnesses that they do not have yet (or which they have, but which may not affect



them for many years to come). For diseases like prostate cancer and breast cancer, predictive and preventative testing currently cannot tell patients with certainty *if* or *when* the cancer will appear or begin to cause symptoms. As such, patients who undergo “treatments” for these conditions (especially prophylactic mastectomy) before they manifest are in essence electing to become cancer patients in advance of their disease. Without these screenings, many people with prostate cancer or the breast cancer mutations would have continued to live without knowledge of their (risk of) cancer and without noticeable symptoms (at least for a significant duration). But because the current screening measures lack the sophistication to know which markers or early abnormal cell developments are harbingers of malignancy and which may remain dormant or benign, some individuals do choose to become cancer patients and receive cancer treatments when they are healthy—and these treatments may put them at greater risk of adverse health consequences in both the long and the short term than if they had never been tested. As a result, these patients become survivors not of cancer, but of cancer treatment.

Especially as genetic testing becomes more common—even being marketed directly to consumers, thus bypassing the provider-patient relationship’s interpretive and intercessory effect—persons may increasingly take on new patient identities which can have a significant impact on their sense of self, future, and autonomy. What’s more, when the condition being tested for is heritable, the disclosure of a person’s status will

often necessarily contain information that goes beyond the individual patient, revealing one's inherent *relationality* through literal genetic ties. As such, this type of testing presents unique challenges and opportunities for bioethics and healthcare.

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