Complicit Care: Health Care in Community

by

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Introduction

“Home is not a favor”[1]

We intuitively think and talk about health care as a human right. But what does this mean? We see the United States fall short of what it could provide given the vast economic, technological and personnel resources available within the country: it spends more dollars on health care per capita than any other wealthy country in the world, but its health outcomes fare worse than countries who spend considerably less.[2] While my focus in these pages will be on the US context, the phenomenon of falling short of global health care commitments is far from only a US problem.[3]

Health care is becoming increasing technologized, yet many simple interventions that would increase health and health care outcomes do not require high-tech tools. They are matters of access to a broad spectrum of resources, more than merely the existence of health care resources themselves: having health insurance, or legal documentation to obtain insurance; basic health care literacy; being connected personally to those working in the health care profession; living in proximity to a medical center; and other environmental and social features that are now known to impact overall health.[4]

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[1] Kgositsile, Keorapetse. “Anguish Longer than Sorrow.” *Black Renaissance/Renaissance Noire* 11.2/3 (Summer 2012): 62.

[2] Research comparing the US health care spending and health outcomes to those of ten other high-income countries revealed that the US spent nearly twice as a much as the next highest-spending country per capita, directing nearly 18% of its GDP to health care. Other high-income countries spent between roughly 9-12% of their GDP, despite health care utilization rates and health care workforce volume being nearly the same across all countries surveyed. The US had the lowest life expectancy and adjusted life expectancy of the 11 countries, and the highest maternal and infant mortality rates. Papanicolas, Irene, Liana R. Woskie, and Ashish K. Jha. “Health Care Spending in the United States and Other High-Income Countries.” *JAMA*. 319.10 (2018):1024–1039.

[3] For example, writing in the Lancet in 2018, researchers note that deaths from non-communicable diseases (NCDs) outpace those from communicable diseases and that progress toward the reduction of NCD deaths to reach targets set by the World Health Organizations (WHO) for 2030 are not on pace to be realized in most countries. “At the current rates of decline in NCD mortality” the set sustainable development goal target 3.4 (to be realized by 2030) is” expected to be achieved for women in 35 countries (19% of all countries) and men in 30 countries (16%). A further 50 countries (for women) and 35 countries (for men) could achieve the target with a slight acceleration in decline.” NCD Countdown Collaborators. “NCD Countdown 2030: Worldwide Trends in Non-Communicable Disease Mortality and Progress Towards Sustainable Development Goal Target 3.4.” *The Lancet* 392.10152 (September 2018): 1072-1088.

[4] Alfandre, David, Sarah Clever, Neil J. Farber, Mark T. Hughes, Paul Redstone, and Lisa Soleymani Lehmann. “Caring for ‘Very Important Patients’—Ethical Dilemmas and Suggestions for Practical Management.” *The American journal of medicine* 129, no. 2 (2016): 143-147. Guilford, Martin et. al. “What Does ‘access to Health Care’ Mean?” *Journal of Health Services Research & Policy* 7, no. 3 (July 2002): 186–88. Hartley,

We tend to talk about health in the language of basic rights or human rights without a clear sense of what such rights mean, let alone whose duty it is to fulfill them. We talk about rights to our own body and our bodily autonomy as justificatory reasons for self-determination about our health and health care, without recognizing the many ways in which our health and health care are deeply enmeshed in the choices, resources, regard, and care, of others. The more we know about health science, the more we know that there are presumably elements of our health within our control (diet, sleep, exercise, which all impact health[5]) though these involve other overlooked privileges that are often not entirely within our own control (access to quality food, adequate supports in our work and home lives that allow time for sleep and exercise, etc.).

We can also better understand what is not (yet) in our control, such as the relationship between genes that are an inherited history influencing our future health, and the epigenetics that lead them to be expressed or suppressed.[6] For a troubling example, research is now revealing a connection between histories of racial injustice and white supremacy that lead black women in the US to experience toxic stress that negatively impacts pregnancy outcomes. Even when adjusting for socio-economic status, including education level and income, the data show that black women have

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David. "Rural Health Disparities, Population Health, and Rural Culture." *American Journal of Public Health* 94.10 (2004): 1675-1678. Larson, Sharon L., and John A. Fleishman. "Rural-Urban Differences in Usual Source of Care and Ambulatory Service Use: Analyses of National Data Using Urban Influence Codes." *Medical Care* (2003): III65-III74.

[5] Casey, Patrick H., Kitty L. Szeto, James M. Robbins, Janice E. Stuff, Carol Connell, Jeffery M. Gossett, and Pippa M. Simpson. "Child Health-Related Quality of Life and Household Food Security." *Archives of Pediatrics & Adolescent Medicine* 159.1 (2005): 51-56. Cook, John T., Maureen Black, Mariana Chilton, Diana Cutts, Stephanie Ettinger de Cuba, Timothy C. Heeren, Ruth Rose-Jacobs et al. "Are Food Insecurity's Health Impacts Underestimated in the US Population? Marginal Food Security Also Predicts Adverse Health Outcomes in Young US Children and Mothers." *Advances in Nutrition* 4.1 (2013): 51-61. Faulkner, Guy EJ, and Adrian H. Taylor, eds. *Exercise, Health and Mental Health: Emerging Relationships*. London: Taylor & Francis, 2005. Laforge, Robert G., Joseph S. Rossi, James O. Prochaska, Wayne F. Velicer, Deborah A. Levesque, and Colleen A. McHorney. "Stage of Regular Exercise and Health-Related Quality of Life." *Preventive Medicine* 28.4 (1999): 349-360. Magee, Christopher A., Peter Caputi, and Don C. Iverson. "Relationships Between Self-Rated Health, Quality of Life and Sleep Duration in Middle Aged and Elderly Australians." *Sleep Medicine* 12.4 (2011): 346-350. National Research Council. *Diet and Health: Implications for Reducing Chronic Disease Risk*. Washington, DC: National Academies Press, 1989. Taheri, Shahrad. "The Link Between Short Sleep Duration and Obesity: We Should Recommend More Sleep to Prevent Obesity." *Archives of Disease in Childhood* 91.11 (2006): 881-884.

[6] Weinhold, Bob. "Epigenetics: The Science of Change." *Environmental Health Perspectives* 114.3 (2006): A160-167. Genes have been historically understood as encoded features of ourselves, outside our immediate control. Epigenetics notes the environmental factors that influence gene express. And with the advent of CRISSPR technology, there is the relatively novel question of whether or not as a human community we ought to control genes themselves, through genetic modification.

worse outcomes during pregnancy.[7] The current hypothesis is that this is due to the stress of living in a highly prejudiced society in which black women are multiply oppressed: as black and as women.[8]

Moreover, research comparing outcomes for pregnant refugee women compared to US-born women indicates that pregnant refugee women have significantly better outcomes for pregnancy and delivery, despite much later access to prenatal care, than either black or white US-born women.[9] The conclusion drawn from this research is that toxic culture in the US negatively impacts pregnant women (regardless of race) as well as their future children, perpetuating lower health outcomes into the future. These present and future health outcomes are due to historical environment: history perpetuates into the present and future. The question of how to take responsibility for our future society, including its health, by taking responsibility for our pasts and present, resides at the core of the following chapters.

The puzzles for this project are twofold: how do we recognize a larger sphere of care as a necessary part of health care? And how do we reframe who has rights to health care, and responsibilities entailed by those rights? My solutions to these puzzles in some ways radically revise the roles of health care institutions, individual accountabilities for others, and communal practices. Yet I contend that although this is an ambitious proposal, it is also a realizable one.

I ask us to look critically at our own practices, our individual failures to recognize and care for others, and our complicity in historical injustices such as social and political exclusions – including, though not limited to, exclusions from health care - that we continue to reproduce today. At the same time my program does not entail envisioning and awaiting large scale political change, or the vast overhaul of political and social systems. Instead, I suggest, we can incrementally work toward and embrace change within our more immediate moral communities, which I formulate as "ethical homes."

My argument in this work hinges on the fact that health care is a social enterprise. Certainly, we can show care toward ourselves, and participate in our own care including regarding our health.

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[7] Kaplan, George A., Elsie R. Pamuk, John W. Lynch, Richard D. Cohen, and Jennifer L. Balfour. "Inequality in Income and Mortality in the United States: Analysis of Mortality and Potential Pathways." *BMJ* 312. 7037 (1996): 999-1003.

[8] This multiple oppression should be understood as intersectional oppression. See Crenshaw, Kimberle. "Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color." *Stanford Law Review* 43 (1990): 1241-1299.

[9] Kafuli Agbemenu, Samantha Auerbach, Nadine Shaanta Murshid, James Shelton, and Ndidiamaka Amutah-Onukagha. "Reproductive Health Outcomes in African Refugee Women: A Comparative Study." *Journal of Women's Health* Online Edition February 15, 2019.

When we have a cold, we might care for ourselves by resting and drinking fluids. Or we might care for our mental health by saying "no" to a project or activity that is not necessary to meet our personal or professional obligations and goals, but would merely cause us anxiety. However, when our cold looks like it might actually be a bacterial infection, or our anxiety is keeping us from our projects and goals, we might seek out the support of others, namely health care resources.

The compound term "health care" refers to a complex set of systems and institutions. I will suggest throughout this project that health care ought to refer to much more than what we usually consider it to be, which is generally related to "medical" systems and institutions. If, as Rawls said, justice is the "the first virtue of social institutions"[10] then justice is a, if not the, cardinal virtue for health care practices, which are a set of related social institutions. To broadly characterize many accounts of what justice is in health care (or just health care, or health care justice, depending on how you frame it) they tend toward two directions.

Down one path, health is a feature we universally have an interest in, and therefore health care is a matter of a human rights agenda. Down another familiar path, health is of specific interest to each of us as individuals, and therefore health care is a matter of just distribution of the limited goods of health care, to which we otherwise tend to have unequal access as individuals (or as groups) given the basic structures of society. Notably, it may not be because we have unequal access that it is unjust, it may be perfectly reasonable to unequally distribute resources, but this depends on the mechanisms for how and why they are distributed.

Down both the human rights and distributive justice pathways, health is what motivates health care. I think this is, in part, an error. In the first chapter I analyze distinctions between health and health care. In the second chapter I assess care, and specifically what kind of care can motivate and participate in an account of justice, rather than run separate and parallel to values of justice. I also propose a new conceptual understanding of health care that amplifies the focus on care. Emphasizing care homes in on health care as a social enterprise. As such, I extend health care beyond mere medical care, to include a series of related social institutions, some of which need to be imagined, or at least reimagined, as social institutions.

The kinds of social institutions I have in mind recast traditional economic or political goods in terms of their inter-relational nature. They are goods of care broadly construed, that amplify the ways in which economic support, political recognition, and care are all relational enterprises

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[10] Rawls, John. *A Theory of Justice*. Cambridge: Harvard University Press, 1971, 3.

reflecting how we relate to things, to places, to each other, and to our moral community. Adequate housing, access to necessary transportation or sufficient nutrition, and the support of compassionate caregivers during a period of illness, for example, could be transformed to reflect the social practices and values of the group in which they occur, rather than viewed merely as economic goods to which one does or does not have access. The focus on care shifts from focusing on fair access to or redistribution of material goods, to focusing on just attention to the value of care, and just attention toward others, achieved through practices of care.

Both human rights and distributive justice frameworks for health care, which I address in more detail in the following chapters, face challenges from empirical studies that point to what are now commonly known as the "social determinants of health."[11] These factors, that include access to goods such as shelter, sanitation, clean water, and sufficient nutrition, but also more dynamic conditions such the level of pollution in one's environment, access to education, level of income and wealth, social class, and racial group identity, all may have more impact on overall health outcomes, when measured by certain morbidity and mortality metrics, than access to medical care. This is a startling finding, for it runs counter to our intuitions about health care, and counter to many of the reasons given for justifying health care. Critics of both human rights and distributive justice frameworks, as we will see in the following chapters, use these social determinants of health findings to alternately strengthen and undermine various justifications for strong claims to health care.

If health is not primarily achieved through health care, then our reasons for addressing health care are weakened. If health is our goal, then justice for health would be through social determinant of health justice, not health care justice. We should focus on human rights to shelter, food, sanitation, an unpolluted environment, and a sufficient income. Or we need to justly distribute not only health care, but also food, shelter, sanitation, income, education, as well as an unpolluted environment, social standing, class and racial identification, etc. And both human rights and distributive justice would need to devise ways to address from within their frameworks the differential benefits and harms of membership along the lines of social class, racial group, or geographic region, that positively or negatively impact health.

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[11] See Thornton, Rachel LJ, Crystal M. Glover, Crystal W. Cené, Deborah C. Glik, Jeffrey A. Henderson, and David R. Williams. "Evaluating Strategies for Reducing Health Disparities by Addressing the Social Determinants of Health." *Health Affairs* 35.8 (2016): 1416-1423 and Adler, Nancy E., M. Maria Glymour, and Jonathan Fielding. "Addressing Social Determinants of Health and Health Inequalities." *Jama* 316.16 (2016): 1641-1642.

Such projects are both ambitious and important: in an ideal world we would want just access to and distribution of not only basic goods, but more complex features of recognition, political membership, and social standing. Yet transforming health care justice into enormous social, political, and economic questions that intersect across many fields of theory and practice does little to help bring more justice to immediate practices of health care in which we, as individuals and as a society, are already deeply enmeshed.

If justice is something owed to each of us, and by us I will mean members of a moral community quite broadly construed (I say much more about this moral community down the road; for now, suffice to say that it is not merely indexed to being human, or being persons, or being rational and reasonable), then health care justice is also owed to each of us. As a practical application, I am not going to suggest with this project that we need to overthrow health care institutions to achieve a perfectly just system.

But I am going to suggest that to do justice with and to health care, we must expand its scope, perhaps radically. By this I mean that we need to extend what kinds of projects and roles are included as health care projects and roles, and which fall within the enterprise of health care. Most crucially, perhaps, I argue that it is health care's function to provide care, not its function to provide health, that lives at the center of health care justice.

Importantly, my expanded definition of health care erodes at traditional, and marginalizing, distinctions between intimate and professional care. I recast often undervalued, uncompensated, and expected care not as private matters of individual choices and opportunities, that reflect affective relationships between friends and family, but as matters of social concern and collective responsibility. When we shift to looking at health care as an expanded practice of care, we also shift our approach to justice. Approaching health care justice alongside a care framework fruitfully changes the course and conversations we have around health care justice in ways that I suggest revolutionize our institutions of health care, in both required and realizable ways.

I build an account of moral community when talking about a moral community that enacts health care justice across these chapters. Health care itself is a micromodel of features that are mirrored by the larger moral community. Health care is relational, it puts at least two, and usually many more, actors (individuals and institutions) in relation to each other to give and receive care. Health care is also a practice. It is enacted and responsive to dynamic and contingent needs. While there are best practices and standards of care in health care, there is not a single framework for health care delivery which can be reproduced for every person in each setting, even for those facing similar diagnoses. Care arises out of the process of responding to each unique patient, person or case.

Care as a practice shares a kinship with my view of moral communities as communities of participatory, contingent practice. In the background of my account of moral community is the expressive-communicative vision of morality articulated by Margaret Urban Walker. Walker describes morality not as theory, but as practice, and therefore moral theory "as an attempt to understand these practices."[12] I take up an attempt to understand, and further a new understanding of, the practices of health care as moral practices within moral communities, in which there are clear rights to and responsibilities for health care.

The account I develop to attribute rights and responsibilities for an expanded vision of health care is through a view of participatory collective cohesion and community bound together via a complicity framework. I call this kind of complicit moral community an "ethical home." I want to be sensitive about how I am using the term "home." Importantly, I am interested in the conceptual nature of "home," and not necessarily its literal iterations in the ways we commonly think of home narrowly construed as a domestic sphere. My view of "home" focuses on how homes are collaboratively constructed among their members. Home is a set of practices and values. These values and practices are made by those who share in a home, and the making of a home is a process through which the members of a home shape its nature, and the nature of the home in turn shapes and defines its members. Home contrasts with the notion of a house. Literal houses are owned and controlled property. Conceptual houses, by extension, are the exclusive control over rights, goods, or membership, that are often built upon a history of privileging some while excluding others.

Feminist scholars have rightly pointed out the ways in which "home" has been aligned with a marginalized private sphere both historically and conceptually. Connecting women to the home in Western society meant that they were absent from public life, left out of intellectual production, political activities, the full rights of citizenship, and much more. We can see this in the ways in which historically women were not full political citizens, and perhaps also not full persons in the philosophical sense of the word. Instead they were able to be oppressed, controlled, and in some instances held as property (such as wives becoming the property of their husbands, not joint partners with their spouses, upon marriage).

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[12] Walker, Margaret Urban. *Moral Understandings: A Feminist Study in Ethics.* New York: Oxford University Press, 2007, 15.

In the second chapter I address ways in which feminist ethics and particularly an ethics of care flipped the script to make many previously marginalized activities relegated to an emotional and private sphere into recognized sites of moral inquiry and ethical theory. Instead of being separate from concerns about morality and justice, feminist scholars suggested that relationships like the mother-child relationship are an exemplar for ethical practice, from which broader public and political modes of ethical engagement can learn and develop. While I also theorize care alongside and growing out of this scholarship, I do not take care to be particular to these kinds of parental relationships or traditional conceptions of home life. Instead, I focus on how practices of care are social, at the interpersonal and societal levels, and are a hybrid of public and private initiatives, values, and practices.

A problem for both of pre-feminist conceptions of home and care as separate from the public and ethical spheres, and for feminist scholarship that re-engages the home and care as fruitful sites of ethical inquiry, is the fact that homes are often non-ideal. Homes can be messy (literally or figuratively), dysfunctional, oppressive, abusive, unchosen, unwelcoming, and places from which we need to escape. I accept all of these features as possible descriptors of a home. Some of the ways in which homes are non-ideal are particularly apt for my own conceptual use of the term. Embracing the non-ideal nature of homes means we can start from a place of non-ideal theory that more appropriately captures what I take to be the lived reality from which we need to generate our ethical inquiry.

When I talk about "home," I am, in some ways, talking about a fairly narrow definition. I engage it primarily as an abstract concept. But in another sense, this makes it a term that can be applied quite broadly. There are many things that homes can be that are not what I take an "ethical home" to be. There are also many iterations of homes that are not ethical, in a non-technical sense: such as those that are abusive, oppressive, or lacking in appropriate care and concern for those who coexist in it. While I am spending some time here at the outset clarifying what "ethical homes" are not, I will over the course of this project, build an account of what they should be. Despite all the ways in which homes can be hurtful or harmful, and the ways in which I risk misinterpretation by choosing the language of "home" for my technical terminology, there are two key features of "home" that commit me to the vocabulary of home.

One is a distinction that I will draw out between two views of rights. On the one view, rights are often tied to having something: standing, property, citizenship. I do not think that the possessive sense of "having" is incidental to these accounts; there is a sense in which rights construed in these ways correlate to ownership over something (ownership over your citizenship and your body are the two cases I explore in detail in the fourth chapter).

I talk about this conceptualization of rights as corresponding to a "house" model of rights, in which houses are goods that are bought, sold, transferred, and controlled. Houses reflect property rights, and property rights are built on what I argue to be an unstable origin story for initial acquisition, which then perpetuate systems of inequity and injustice through the practices of ownership. I contrast this model of "house" rights with a model of "home" rights, according to which I take "homes" to be things that are made, rather than things that are owned. A key distinction between a house and a home is that a house is a good to be controlled, whereas a home is a process in which members participate in home-making.

This leads to the second feature of "home" that I endorse in these pages. I understand "homes" to be constructed, and continually reconstructed, through the participation of those recognized as members. While membership can and does still have exclusionary and unjust practices in terms of who warrants regard or inclusion as a member, homes invite the possibility for remaking and rectifying these injustices. Homes are more plastic in that they are co-constructed among those participating in them, and can be continually redefined by that community as it expands to include new members, or contracts to exclude those who fail to meet their obligations as members. My claim is that rights are better viewed as products made within conceptual homes, as constructed and endorsed by a community of rights-holders, who are also responsible for protecting and fulfilling such rights.

I engage a model of complicity to think about homes as generating an ethical framework for rights and responsibilities. Understanding that we are complicit in the various kinds of "homes" in which we are members, whether that be a traditional home among families, or a conceptual home in our larger social and political communities, is a tool for understanding how we are responsible for others internal to our homes. Complicity is an assessment of individual contribution to collective action.

We tend to think of complicity as a pejorative term to assess blameworthy responsibility in a collective harm. However, I provide an account of how complicity also functions in a positive light for generating duties to others with whom we share our ethical homes. The backward-looking nature of complicity as assessing historical wrongs and harms is also what makes it a forward-looking entailment of obligations to others. In this way, I take complicity to be an appropriate, though underdeveloped, opportunity to extend an account not only of individual contributions to collective harms, but individual responsibility to contribute to collective action.

To provide a roadmap of this project: The first two chapters establish why I am committed to a view of health care justice instead of health justice, and what kind of account of care I am talking about when talking about health care. In the first chapter I draw an important distinction between health and health care, one that is often taken for granted in the literature, and which tends to collapse the two terms into the same concept. In the second chapter I consider care theory, and provide an account of care that is an enactment of justice, rather than parallel to or separate from justice. These two chapters provide the foundation for my theory of health care justice, for which I argue there are specific rights, which are stronger than we tend to recognize. These rights also yield correlative responsibilities within specific moral communities, and the obligations of individuals and institutions within these communities are broader than we tend to think.

The third and fourth chapters set up my view of rights that inform the kind of rights account I take to generate duties to provide health care. In the third chapter I explore the concept of rights, including claim-rights, property rights, and human rights. In the fourth chapter I engage two iterations of a case about an undocumented pregnant person's rights to health care in the United States. Both versions of the case illustrate why rights frameworks rooted in universal human rights, or narrow individual rights such as to self-ownership, are both theoretically tenuous and practically unsatisfying for health care. It is in the fourth chapter that I establish the distinction between a "house" model of rights, that I reject, in order to propose a "home" model of rights built on a different type of rights framework and moral community.

The fifth and sixth chapters develop my account of a rights framework based in the concept of an "ethical home." Chapter five primarily engages with the complicity literature, as well as moral partiality literature, to suggest that complicity is a tool to define particular moral communities. There I make a case for a positive view of complicity as not only entailing individual attribution of blame for collective harms, but also entailing individual accountability to care within collectives. I advocate for communal complicity for collective action, and particularly the collective response demanded by just health care. The fifth chapter concludes by motivating an example of health care policy and practice with heart transplant recipient listing criteria.

I conclude the project in the sixth chapter by arguing for why complicity establishes moral communities that generate both rights and responsibilities, and why these moral communities are best described as "ethical homes." I return to the example of heart transplant recipient criteria to show how current guidelines for heart transplant recipient criteria reflect a “house” models of rights and responsibilities. I show how this model is susceptible to reproducing historical injustices and social exclusion. In response, I propose how an “ethical home” model would reframe the criteria to receive a donor heart in order bring it in line with more just, ethical, and caring practices.

By taking up central question of health care justice in the case of the heart transplant criteria, and throughout the chapters leading up to it, I am not merely applying theory to practice, but rather showing how the practices give rise to an occasion to challenge and reconfigure our norms, such that theory and practices collaborate with each other to foster the mutual expression and refinement of each, rather than one being a shoot that emerges out of the other’s roots.

I

The Health in Health Care

Health is a difficult concept to track. In this chapter I argue that "health" has problematic implications for a just rights-to-health framework. At best, "health" is too broad to establish clear rights and responsibilities. At worst, "health" has harmful implications that risk promoting injustice. In this chapter I ask: what is health? In the next chapter I ask: what is health care? My objective is to show what it is about "health care" as a compound term that is distinctively valuable. In this and the next chapter I defend the concept of health care, as opposed to a concept of health. I do this in two ways.

One, I argue that the practice of health care, rather than a value or concept of health, best motivates health care justice. By extension, meeting demands of health care justice also addresses broader questions of justice. Two, I argue for an expansive definition of what constitutes health care. I distinguish health from health care by looking at two common approaches to defining health. On one account, as promoted by the World Health Organization (WHO), health is a broad concept whose reach extends to total well-being. On another account, which reflects a narrow biomedical perspective, as exemplified in Norman Daniels's account of health and distributive justice, health is species-typical functioning, and the absence of pathology.

These appear to be two extreme poles along a possible health-definition spectrum. However, they are not straw definitions I set up merely to knock down. Both the WHO and the species-typical functioning accounts prominently inform health policy and theory. Yet both of these accounts make for an uncomfortable marriage of theory and practice, where the theory yields severe limitations on the practice, and the practice reveals shortcomings of the theory. Although the WHO and species-typical functioning definitions of health are quite distinct, they fail for some similar, though also some different, reasons which I elaborate. Both definitions share the feature that they do not produce the kinds of justice they aim to address.

In this chapter I conceptually analyze the term "health," and its agnate concepts of "well-being" and "healthy," through the lens of two prominent programs for health proposed by the WHO and the species-typical functioning accounts. Both of these definitions underpin programs for health care justice, based in the premise that health care is justified by its role in promoting and protecting health. So, the arguments go, given the special value health has to individuals (and populations), we have obligations to provide just access to, and distribution of the goods of, health care. In these accounts, "**health**" care is not interchangeable with "**medical**" care, yet I suggest in the next chapter that they nonetheless too narrowly construe "**health care**." I propose instead a more radical revision of the content and scope of health care. In this chapter I show that the spurious definitions of health engaged by the two mainstream approaches I consider cannot meet the demands of justice they intend to uphold. And, more worrisome, we will see that in certain cases these definitions of health risk doing further injustice.

Health as Complete Well-Being

The World Health Organization (WHO) was formed between 1946-1948, out of the belief, for reasons Hasting Center co-founder Daniel Callahan describes as uncertain, that "world health would make an important contribution to world peace."[1] The WHO defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[2] Callahan says the definition "provides such an irresistible straw man" for scholars to quickly attack in order to pursue "more profound reflections" on a definition of health. Yet he adds that knocking down the WHO definition on the path to another agenda overlooks potential merits of the WHO definition.[3]

The WHO definition of health was taken up by the "Declaration of Alma-Ata" in 1978, a product of a conference on primary health care.[4] It was not the definition of health included in the International Convention on Economic, Social, and Cultural Rights (ICESCR), which establishes in international law a human right to the "highest attainable standard of health,"[5] although like the WHO definition, the ICESCR also offers a broad vision of health. The right to the highest attainable standard of health is not a right to be healthy, but it encompasses more than mere medical care. ICESCR companion document, General Comment 14, enumerates the ways in which states are uniquely responsible for the protection and fulfillment of human rights, including human rights to health. It also specifies that rights to health include a package of goods including: shelter; nutrition

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[1] Callahan, Daniel. "The WHO Definition of 'Health.'" *Hastings Center Studies* (1973): 77-87, 79.

[2] Ibid., 77.

[3] Ibid.

[4] World Health Organization. "Declaration of Alma-Ata" (1978) accessed January 4, 2019 at https://www.who.int/social_determinants/tools/multimedia/alma_ata/en/

[5] International Covenant on Economic, Social and Cultural Rights, Article 12, January 3, 1976. Accessed November 27, 2018. https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx.

and hydration; sanitation; and an adequate living wage.[6] I say more about these international human rights documents in chapters three and four, when evaluating human rights to health in detail.

Like the ICESCR and General Comment 14, the WHO definition of health extends beyond a mere medical realm. The WHO definition reaches even farther than the ICESCR because it takes a global view of health as complete well-being, without qualification, and explicitly extends it to mental and social aspects of well-being, in addition to physical well-being. The WHO definition easily accommodates what research in the late 20th and early 21st century identifies as the social determinants of health,[7] by recognizing that many other non-medical factors are preconditions for, and contributors to, one's overall experience of "health" (in the language of the social determinants of "health") or well-being (in the language of the WHO definition of health).

By specifically including social and mental well-being its definition, the WHO suggest that nearly everything about one's social, economic, and political world, in addition to physical and environmental aspects, contribute to health. At the same time, the precise meaning of health (or well-being) loses some of its force when the definition of health is diluted to include everything about our lives.[8] It may lead us to wonder if health and well-being are synonymous, or if there is a relevant difference to health that is more specific than, or distinct from, well-being.

Well-being is also a contested term. In contemporary English Aristotle's term *eudaimonia* is translated as either "well-being" or "flourishing." This already suggests that well-being is flourishing, and rather than clarify what we mean by well-being, it invites the question: what do we mean by flourishing? Writing in the context of well-being discourse and disability, Elizabeth Barnes notes that "there are many quite disparate theories of well-being."[9] Barnes appears to allow for a pluralist view of well-being, and indicates that Aristotelian objective-list accounts of well-being tend to construe disability as counter to well-being, not because of a feature internal to the objective-list view, but

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[6] United Nations Committee on Economic, Social and Cultural Rights. "General Comment No. 14, The right to the highest attainable standard of health." August 11, 2000. Geneva: United Nations, 2000. Accessed December 21, 2018 https://digitallibrary.un.org/record/425041.

[7] Daniels, Norman. *Just Health: Meeting Health Needs Fairly.* New York: Cambridge University Press, 2008, 21 and 43. See also Thornton, Rachel LJ, Crystal M. Glover, Crystal W. Cené, Deborah C. Glik, Jeffrey A. Henderson, and David R. Williams. "Evaluating Strategies for Reducing Health Disparities by Addressing the Social Determinants of Health." *Health Affairs* 35.8 (2016): 1416-1423 and Adler, Nancy E., M. Maria Glymour, and Jonathan Fielding. "Addressing Social Determinants of Health and Health Inequalities." *Jama* 316.16 (2016): 1641-1642 for select recent scholarship on social determinants of health.

[8] Callahan, 80; Weinstock, Daniel M. "How Should Political Philosophers Think of Health?" *Journal of Medicine and Philosophy* (2011): 1-12, 10.

[9] Barnes, Elizabeth. *The Minority Body: A Theory of Disability*. New York: Oxford University Press, 2016, 60.

rather as a product of them.[10] Barnes takes a mere-difference view of disability. This view is particularly problematic for a species-typical account of health that I address in the next section. But if her view of disability as mere-difference is correct, it problematizes the concept of health as a "state of complete well-being" if a view of well-being cannot be value-neutral toward disability.

Arguably traditional medical practices make an implicit assumption that well-being is connected to a particular vision of species-typical functioning. A commonly adopted assessment tool for well-being is the RAND 20: a short-form of 20 questions that assess a respondent's perceived well-being.[11] The tool was initially designed to gauge outcomes for chronically ill patients interacting with health care systems, but continues to be used to assess self-reported well-being among both ill and not-ill individuals.[12] While the questionnaire nowhere directly asks respondents to assess their "well-being," it makes inferences about their well-being from reported perceptions about individual health, performance of a specific selection of daily functions and activities, and self-reported mood or general disposition. This equates a specific account of standard functioning with "well-being," and also suggests that well-being is a product of species-typical health (and is compromised by the absence of species-typical functioning), but not that health is a product of well-being.

More recently, Rachel Dodge and colleagues surveyed definitions of well-being, which they describe as a multifaceted concept, to conclude that most accounts address dimensions of well-being rather than a concrete definition of the term.[13] In contrast, Dodge and colleagues asserted their definition offers a "simple, universal application" and a "basis for measurement" that attends to the notion that balance and equilibrium change across life events or challenges.[14] Positing well-being as dynamic addresses one line of argument against the WHO definition that health is a "complete state of well-being" in which a "state" is read as a fixed status, and complete indicates a stable whole, instead of allowing for partial or episodic well-being.[15] Dodge et al. define well-being as "the balance

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[10] Ibid., 62.

[11] Rand Corporation. "Medical Outcomes Study: 20 Item Short-Form Survey Instrument." https://www.rand.org/health-care/surveys_tools/mos/20-item-short-form/survey-instrument.html

[12] Stewart, Anita L. *Measuring Functioning and Well-being: the Medical Outcomes Study Approach*. Durham: Duke University Press, 1992.

[13] Dodge, Rachel, Annette P. Daly, Jan Huyton, and Lalage D. Sanders. "The Challenge of Defining Wellbeing." *International Journal of Wellbeing* 2.3 (2012), 222. They note that among other issues is the disagreement whether it is "wellbeing" or "well-being." They defer to the former; I deploy the latter.

[14] Ibid.

[15] Frenk, Julio, and Octavio Gómez-Dantés. "Designing a Framework for the Concept of Health." *Journal of Public Health Policy* 35.3 (2014): 401-406, 402. See also Bircher on a dynamic concept of health: Bircher, Johannes. "Towards a Dynamic Definition of Health and Disease." *Medicine, Health Care and Philosophy* 8.3 (2005): 335-341.

point between an individual's resource pool and the challenges faced," in which resources include psychological, social, and physical factors, and challenges also include this same range of psychological, social, and physical factors.[16] These factors can and will develop, build, or modify across time as one's resource pool and challenges evolve.

However, this account of supposedly simple and universal scope reveals the very problems with well-being that make it problematic for defining health, especially a definition of health that would entail clear rights and responsibilities. Dodge and colleagues suggest that their model of well-being is universal because it addresses the ways in which resources are individual and context specific. What they have created is a transportable formula for well-being, according to which the content of the definition will change from individual to individual or from context to context. While they may have offered a universal formula for generating local definitions, they have not in fact offered a universal definition of well-being. Their attempt at producing a universal definition underscores the pluralism of values and opportunities that impact any notion of well-being.

Moreover, on their view, well-being is "in the hands of individuals by teaching them that they can increase their resources or challenges to maintain a sense of equilibrium," but it also expects one to make the best of what she has by accepting the parameters of her resources.[17] This view might be an acceptable exercise in positive-psychology. But as an account that could motivate rights to health care and health care justice, it overlooks the ways in which agents are often not free to choose or increase their resources. In the next chapter I spend much more time exploring the notion of choice and how an emphasis on individual choice misrepresents much of what is unchosen about our circumstances. And across all chapters I trouble the ways in which conversations about health care in particularly can erroneously hinge on the vocabulary (and mythical assumption) of individual choice.

As matters of justice, issues of injustice and inequity ought not be downgraded to making the best of a bad situation or accepting and working within one's constraints. Focus on individual, independently-produced well-being follows from philosophical commitments, which bioethics tends to uphold, to individuals as the agents of choice and action.[18] What gets lost are the ways in which agents act within social structures, as well as the ways in which many of the apparently autonomous

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[16] Dodge, 230.

[17] Ibid., 231

[18] Anspach, Renee R. *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley: University of California Press, 1997.

choices individuals are tasked with making in bioethical dilemmas are already shaped by the context that cultivates the very range of options available to them.

The terms we turn to talk about health: well-being, value, quality of life, are often subjective terms. We each arrive at a different assessment of what is a valuable life, or an acceptable quality of life. We have different criteria for assessing our own well-being, or how we perceive the well-being of others. But moreover, these concepts are also often incommensurable.

When starting from health care practices, the term "quality of life" is frequently used to justify medical decisions. We might say that quality of life is vaguely connected to well-being. But it is also normative (and I discuss the very notion of normativity in detail when I turn to the species-typical functioning view of health) and value-laden. Future quality of life, for example, is a justification provided for withdrawing or withholding life sustaining treatment from newborns who have projected "serious physical or mental disabilities."[19] Different criteria for "quality of life" might lead to an argument in favor of resuscitating that same newborn, and offering all available life-sustaining therapies.

In these kinds of decisions, the questions of whose quality of life is being considered, and according to what criteria, remain opaque. The phrase "quality of life" might stand in for beliefs about the value of living a life with physical or mental impairments, or a life caring for a child with physical or mental impairments, for example. Advance directives ask individuals to select what kinds of hypothetical physical and mental conditions would be acceptable qualities of life. That people make different selections reflects the wide range of values and preferences one might hold regarding quality of life. But we also use the phrase "quality of life" to talk about our non-medical selves: we can talk about the quality of life we can afford on our current salary; the quality of life our job allows us regarding work-life balance; choosing to move to a particular city because of the quality of life it offers; or discrepancies in quality of life around the globe. Each use of "quality of life" is measuring and weighing (and reflecting) slightly different considerations, priorities, and values.

The unique pleasures and priorities of each person contributes to her subjective vision of a life-worth-living, and her quality of life. There is not a fixed checklist of what content is relevant for each individual's assessment of her quality of life. Although we might have overlapping criteria for

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[19] Ibid., 30. The "Baby Doe" regulations were developed in the 1980s to respond to withdrawing or withholding treatment based on perceived quality of life (Anspach 170-171). However, guidelines from the American Academy of Pediatrics, the recognized "standard of care" within medical practice, and subsequent case law have not endorsed these regulations. See White Michael. "The End at the Beginning." *The Ochsner Journal*, 11.4 (2011): 309-16.

determining quality of life, we each invoke features that matter to us.[20] The various values we each have regarding our own qualities of life are largely incommensurable. Quality of life means more than health, and health is not identical to quality of life. Here the WHO approach has something to recommend it: appeals to quality of life support a view of health as a broad concept, not merely measured by specific qualitative or quantitative indices of health (which might differ depending on the setting, purpose, or target of the measurement). Quality of life is yet another vague concept that aptly captures value pluralism and context plasticity, but does not produce a clear definition.

For these reasons, well-being as a definition of health is a non-starter. Or rather, it does not move us any closer toward a precise definition of health that can motivate a theory of health care justice with institutional norms and practices, and defined rights and responsibilities attached to these norms and practices. Health as complete well-being simply means whatever one's account of well-being would have it mean. Such a theory of well-being might already contain assumptions about justice.

Callahan, I believe rightly, observes that the WHO definition of health results in "a tautological proposition that health is the absence of non-health, a less than illuminating revelation"[21] Perhaps this kind of value-pluralism about well-being is necessary for a global definition of health that can accommodate different realities and capacities between states, and therefore rightly allows for subject-specific and context-specific operative definitions of health that can all be captured in an overarching account. (In the final section of this chapter I argue in favor of value-pluralism about health, in addition to value-pluralism about well-being, though propose we can still be more precise about health care in a way that accommodate value-pluralism about health.)

Defining health by well-being either requires committing to an account of well-being to arrive at an account of health, or it forces us to dive into the deep end of a long-standing debate about well-being to answer the question: "what is health?" Either route provides little practical guidance or institutional purchase for establishing concrete practices of health care with an eye to justice. Even if we practice substantive over procedural justice, which I think we should, substantive justice is not subjective justice. And even if we could arrive at an overlapping consensus for well-being and therefore health, it will be likely be too broad, and therefore too weak, an account to

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[20] Elizabeth Anderson has made a compelling case for value pluralism, and the kinds of questions we need to ask of justice in light of value pluralism. My own views about value pluralism are indebted to her rich and insightful analysis of value. Anderson, Elizabeth. *Value in Ethics and Economics*. Cambridge: Harvard University Press, 1995.

[21] Callahan, 85.

attend to the concrete, immediate needs to which health care responds, and the challenges that health care presents. A shortcoming of the WHO definition of health (as well as the "highest standard of health" definition from the ICESCR) is that it does not yield particular demands that can be translated into rights claims, nor pick out individuals or institutions accountable to bring about this vision of health through correlative duties.[22]

That the concept of health might simply remain vague, or generalized, is not necessarily a problem with the WHO definition of health.[23] Perhaps to capture an apt description of health, one that recognizes it will be informed by a range of plausible yet diverse accounts of well-being, and will be adapted to variations in social and cultural expectations and resources, it must remain vague. This allows a definition to aptly capture the views of a plural world. Being pluralists about health (and well-being) also accommodates the view that "being healthy" can mean different things depending on the context.

Elizabeth Barnes draws on Kris McDaniel's account of concepts "unified by analogy"[24] to assert that "exercise, broccoli, Stephen Curry, and my marriage are all healthy – but arguably there's no single property they all share in virtue of which they are healthy."[25] Barnes's point is that we can equally well describe activity, food, professional athletes, and intimate relationships by the same term, even though they are different kinds of things (actions, objects, persons, and connections). Given the very different kinds of things we can describe as "healthy," were they to share a common property, McDaniel points out, the feature "in virtue of which we exemplify this common property differs from case to case."[26]

Does the variety of ways it is possible to be healthy, or the various things that can be healthy, bolster a plural account of health as well-being? I want to explore one way in which "healthy" as a term unified by analogy is unhelpful for conceptualizing health, and one way in which it might contribute to a better understanding of health. On the one hand, the idea that the term "healthy" is

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[22] As I discuss in chapters three and four, these human rights focused approaches name states as the primary agents with obligations to respect, protect, and fulfill human rights claims. In those chapters I challenge that states can and should be only agents with correlative duties. Here my point is more to critique the ways in which an abstract concept of health cannot generate particular claim-rights, and therefore cannot generate particular obligations to respond to claims, whether the obligations would be held by states, individuals, or non-state institutions.

[23] Callahan notes that we engage vague concepts all the time. See Callahan, 78.

[24] Barnes, 2.

[25] Ibid., 3.

[26] McDaniel, Kris. "A Return to the Analogy of Being." *Philosophy and Phenomenological Research* 81.3 (2010): 688-717, 696.

unified by analogy might say something about being "healthy" without filling in much content around the concept of health. On the other hand, across unified, analogous instances of "being healthy," we might see certain qualities that point to normative operative assumptions about "health," and are descriptive about our use of "health," even if not prescriptive for how we ought to define it.

First, it is possible the term healthy as an adjective might do different work than health as a noun. Barnes proposes that the concept "disability" is unified by analogy similarly to the way the concept "healthy" is unified by analogy.[27] Interestingly, some of her critics suggest that Barnes constructs disability as a concept that is distinct from, and may not closely track on to, experiences of being disabled.[28] This distinction means it is possible to talk about the concept of disability apart from the lived experience of being disabled.

With such a distinction in place, it looks like disability functions more like the concept "health" rather than the experience of "being healthy." So perhaps (being) "disabled" and (being) "healthy" are both terms unified by analogy. We can use terms like "healthy" or "disabled" to talk about a variety of things that are not human bodies, and convey meaning about these things. The meaning contains an element, though, of a core concept, to which the analogy connects.

I can talk about the economy being healthy or a capability on my computer as disabled because they refer back to a core concept. That the core concept is a normative one (and may also be problematic, inaccurately descriptive, harmful, or even empirically unfounded) does not negate that the adjectival form of the concept can do linguistic work. It reflects the normative concept. That adjectives are unified by analogy does not necessarily reveal an important truth about the definition of the core concepts to which they refer. But it might reveal implied value-laden content embedded in the terms.

In my examples of the economy being healthy or a computer function being disabled, my adjective choices are not necessarily describing the economy as good or my computer as bad. Perhaps I could also say the economy is "strong," "robust," or "flourishing." I might also think, because I have investments, or because I am seeking a job, that a healthy economy is also a good thing. But this does not mean that the concept of health is identical to being strong, robust or flourishing, even though I can use these terms in place of the adjective "healthy." At the same time,

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[27] Barnes, 3.

[28] Campbell, Stephen M., and Joseph A. Stramondo. "Review of Elizabeth Barnes, *The Minority Body*." *Notre Dame Philosophical Reviews* (2016).

we also might associate those features with a notion of health, and this suggests that we attach a great deal of normative content to "health."

In the case of the computer function being disabled, by using this term I might be communicating that I turned something off, say the internet connection, so as not to be distracted by incoming emails while I work. The internet function is currently disabled, and this conveys a departure from the regular functions of the device. I have chosen to turn it off, and it is temporary.[29] Using the term "disabled" refers only to this changed level of functioning. This is not a pejorative description; in fact the disabled function is a helpful change. Using "disabled" in this way concurs with Barnes's account of disability as mere-difference. On her view: "having a disability is something that makes you different, but not something that by itself makes you worse off because of that difference. Being disabled is simply something that makes you a minority."[30]

It is not disability that is bad, or being disabled (if her critics are correct that the concept and the experience of disability are distinct, and if I am correct that the concept and the adjectival forms of terms are not necessarily equivalent) that is bad. Disability is merely a way of being different from others, of having less common (that is to say, minority) features. It is the way society has constructed a world that cannot accommodate disability that leads disability to make one worse off. Being made worse off by disability is not inherent to disability, or even to society.[31] Society could, and should, be shaped differently.

These observations connect to my second point that "healthy" as a term unified by analogy describes uses of health and reveals normative content which we may or may not wish to retain were we to establish a prescriptive definition of health. We can talk about our marriages, the economy, broccoli, and professional athletes all as healthy, and this conveys meaning, but this meaning is not necessarily that they are either in a complete state of well-being, or that they are typically-functioning. As Barnes talks about with regards to Olympic athletes, there are cases in which minority function is what causes someone to excel athletically. The economy might be healthy because it has departed from its standard course. Marriages or other intimate relationships might be satisfying because they don't fit with commonplace (and historically patriarchal) norms of marriage.

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[29] I would venture, though, that if I hadn't chosen this, and it was not temporary, I would not only see this neutrally, but negatively. However, the term "disabled" might no longer be apt. I would describe the computer instead as "broken."

[30] Barnes, 78.

[31] Barnes, 78.

And some foods, like almonds, might be healthy to the human body (unless you are allergic to nuts), and yet unhealthy toward the environment due to farming requirements and practices.

Almonds can be partially healthy, or contextually healthy, without referring to a complete state of health. Anyone who has ever read a mainstream media article about nutrition, been around anyone who has ever gone on a diet, or has heard anything about "wellness" culture knows that in colloquial conversation qualifiers like "healthy" often express value-laden judgements that something is "good," as opposed to "unhealthy" foods/activities/behaviors that are "bad." We frequently signal value-based normative content with these terms, though it need not be the case. Furthermore, whether at the colloquial or conceptual level, there may be good reason to remain broad, plural, and value-neutral about terms such as "health" (or "disabled") and recognize that these concepts do different work in different contexts.

To be clear: I am not arguing that a vague concept of health is a problem simpliciter. I endorse pluralism about health, and expand on this view at the end of this chapter. A particular problem, however, arises when vague concepts like health are used to motivate specific account of rights. In those cases, health is supposed to pick out a package of obligations owed and due. This becomes a particularly fraught issue with human rights frameworks, and specifically for a human right to health, both of which I address in detail in subsequent chapters.

Given the shortcomings of a broad definition of health as complete well-being to set an agenda for health care justice, is it possible to arrive at health care justice with a concept of health as its starting point? Next, I turn to an account motivated by a different concept of health, one that narrowly construes health as putatively "normal" species functioning. This definition of health is intended to motivate an account of health care justice. The thought is that to define the parameters of just health care, we first need to know what health is. Yet a species typical definition of health is indebted to available practices of, and values internal to, health care and medicine, which set the parameters for what separates the species typical from atypical. On this view, using health to define health care gets caught in a tautology where health care also defines health.

Species Typical Functioning and Distributive Justice

Norman Daniels argues that a right to health care is only warranted once there is an established "theory of justice for health care" or a more "general theory of distributive justice."[32]

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[32] Daniels, Norman. *Just Health Care.* New York: Cambridge University Press, 1985, 5.

Daniels engages with John Rawls's framework of justice as fairness to arrive at a theory of distributive justice for health care. In order to produce a just distribution of health care goods, Daniels claims we need an account of why health care is "special." He argues for this specialness because health care protects a certain kind of health, which in turn promotes fair opportunity. However, his proposal for health care justice hinges on a problematic account of health, which has harmful, and in many ways unjust, implications for practices of health care.

According to Daniels, the language of individual rights claims to health is a common, but inappropriate, way to engage a discussion of justly reforming health care systems. He argues that starting from a presumption of individual rights to health or health care cannot clarify the "scope and limits of such a rights claim," and tends to produce disagreement about the scope and limits.[33] Related to a right to health care, a right to health: "should be construed as a handy way to characterize **functionally** the category of actions about which one is making a claim." It should be about promoting fair equality of opportunity. Nonetheless that equality of opportunity is motivated by a particular conception of health for Daniels.

Daniels acknowledges that rights to health would include "a broad range of actions that affect health - say, protection of the environment, even if these actions are not normally construed as health-care services."[34] Yet for his purposes, Daniels very narrowly defines health, even if he recognizes that what protects health includes goods and services that tend to fall outside of immediate health, or even outside of health care resources. A species-typical vision of health is foundational to Daniels's conceptualization of equality of opportunity.

It is important to underscore that even if "health" is what is being protected and promoted, it cannot be realized without various forms of care, though this aspect of Daniels's view is not one he himself emphasizes. He instead focuses on goods and services, and comprises health care of goods and services without an eye to how or if goods and services feature in care.[35] He does point out that a right to health care can "imply quite different things, both with regard to the **scope** of

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[33] Ibid.

[34] Ibid., 6.

[35] While I will defend a view of care as a relational practice in the next chapter, at this juncture I think we can generally understand care to be an act, a disposition, and a set of practices, depending on the context. In this way "care" might be like "healthy" a term unified by analogy, in which certain properties are shared across various uses of the term. The reason why I think we can characterize care as containing all of these facets for an analysis of Daniels is that he does not invoke any of these features when speaking about health care. Health care is more than medical services for Daniels, though it is exclusively comprised of either goods or services (Daniels, *Just Health Care*, 32).

what is being claimed and with regard to the type of justification it needs,"[36] particularly between a right to access existing goods and services, or a right that demands the establishment of new goods and services.[37]

Although Daniels picks out a specific definition of health that is more actionable and concrete than the WHO definition, what is being expressed in "a right claim to equal **health** is best construed as a demand for equality of access or entitlement to health **services** - where these may include preventative and environmental measures."[38] Daniels distinguishes a right to be healthy from a right to access health services that would promote, restore, or protect health. And while it is the right to access services, not to the state of being healthy that motivates his account, nonetheless (a particular kind of) health care as a right is generated by (a certain vision of) health.

For these reasons, it is necessary for Daniels to establish what kind of social good health care is: whether health services are goods like any other, or if health care is "special" and not something to be exchanged on a market like any other commodity.[39] What makes health care special is its role in promoting health related to opportunity. Daniels distinguishes health care goods from other goods because there is a difference between preferences (and the goods exchanged out of desire or preference) and needs, which he says have a direct effect on opportunity. Because in a just society fair opportunity would be justly distributed, health is valuable because it protects fair share of opportunity, and therefore "if there is a right to health care, it is because of the **kind** of social good health care is, the **kind** of needs it meets," which is to protect health, and in so doing, promote fair opportunity.[40]

Promoting opportunity requires a particular kind of health for Daniels. He takes a species-typical functioning or biomedical approach to health. In *Just Health Care*, his definition of health was "the absence of disease," and diseases are "deviations from the natural functional organization of a typical member of a species."[41] Deviations from natural function include those that arise out of biological or environmental reasons, as well as "deformities and disabilities that result from trauma."[42] Thus, disease encompasses conditions originating internal to one's body, either at birth or

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[36] Ibid., 8.
[37] Ibid., 7.
[38] Ibid. All emphasis is in the original text.
[39] Ibid., 10.
[40] Ibid., 12. Again, emphasis in original.
[41] Ibid., 28.
[42] Ibid.

during the lifespan, but also those that are produced by external factors such as accidents, violence or environmental contaminants.

Revising his views in 2008, Daniels maintained this same account but changed the term "disease" to "pathology," suggesting the latter tracks onto common usage more accurately.[43] Both terms are meant to include "disability and injury."[44] Daniels takes this view of health to be a theoretical and statistical account of what is normal, and suggests it is the role of biomedical sciences to determine the "natural functional organization" of the human organism,[45] which can be objectively measured.[46] That is to say, he understands this definition of health to provide an accurate theoretical account, but allows for biomedical sciences to fill in and fix its precise content.

There is a curious relationship between perceived empirical fact and social context in Daniels's account of health and the rights to health care that follow from it. He concedes that we have "biological goals as **social** animals," yet his account of health is not intended as a social definition.[47] Normal species functioning is important because of its connection to range of opportunity, yet "normal opportunity range is socially relative" depending on features related to where one lives, levels of wealth and development, and various cultural facts.[48]

Equality of opportunity is also dependent on "talents and skills" such that not all persons have equal needs, but when corrected for natural talents and skills (and contextual features that make some talents and skills contextually relevant) needs are to be met in a way that is "**fair** to the individual."[49] Daniels anticipates the objection that what appear as natural talents and skills may be driven by implicit social features and inequalities. To mitigate this, he suggests, we need to equally address underlying social inequities such as racial and economic inequities. Health care justice on his view, and which he acknowledges, cannot be separated out from social justice.[50]

Even if Daniels's did come to recognize that there are many factors that contribute to health, expanding his basic list of health needs to include a sixth category of the "social determinants of health," he concludes that health needs are "objectively ascribable,"[51] and this objectivity is possible

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[43] Daniels, *Just Health*, 37.
[44] Ibid., 36.
[45] Daniels, *Just Health Care*, 28.
[46] Daniels, *Just Health,* 37.
[47] Daniels, *Just Health Care*, 29. Emphasis from Daniels.
[48] Ibid., 33.
[49] Ibid., 33. Emphasis his own.
[50] Daniels, *Just Health*, 4-5, 6.
[51] Ibid., 43.

because of his narrow commitments to a species-typical functioning account of health. Health care needs reach beyond merely access to a traditional medical system, and include: "1. Adequate nutrition, shelter; 2. Sanitary, safe, unpolluted living and working conditions; 3. Exercise, rest and some other features of life-style; 4. Preventative, curative, and rehabilitative personal medical services; 5. Non-medical personal and social support services." These needs are part of a larger social justice agenda, but their purpose related to health care is to support biological functioning, not a general sense of well-being.

Daniels recognizes that opponents see his definition of health as too narrow compared to a broad WHO definition that includes complete well-being across physical, mental and social spheres. He charges back that that the WHO definition is a theory of happiness instead of health.[52] He is correct to try to pick out a theory of health care justice that is not merely a theory of general happiness or well-being if we want to specifically pursue health care justice. But if we see health care justice in the service of social justice, then his critique of the WHO definition of health because he says it is "social philosophy"[53] is unwarranted: his account is also a social and political enterprise.

He also anticipates opponents who charge that his concept of health is a normative, and not descriptive, or biological, model.[54] Daniels responds to this critique by proposing a distinction between illness, which he sees as normative, and disease (or pathology as per his revised view) which is descriptive.[55] He portrays this illness/disease dichotomy as creating a distinction between the socially constructed, and therefore "normative" category of illness as opposed to a biological, scientific, and therefore "descriptive" category of disease (or pathology). He also equates normativity with evaluative judgements. The reproductive examples Daniels uses to illustrate his purported distinction between illness and disease/pathology, however, are rife with contradiction. These examples illustrate that for Daniels, normativity means both social construction and social value, or desirability.

Yet there are at least two kinds of normative projects. The first layer of normativity is the constructed nature of norms. "Normative" signals that norms are not received from intrinsic properties of things (such as the nature of humanity, in the case of human rights, which I take up in later chapters). If they were, then we would be producing a descriptive or naturalistic account that

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[52] Daniels, *Just Health Care*, 29.
[53] Ibid, 29.
[54] Ibid, 29.
[55] Ibid., 30, Daniels *Just Health*, 36.

reflects the inherent nature of the thing. To establish practices arising out of descriptive accounts would be to analyze, reveal, or uncover the correct nature of the thing, in order to arrive at the principles and practices associated with it. Normative projects, however, establish principles and practices that reflect and produce the nature, but also the value, of things.

Moral communities develop and reinforce norms. Naturalistic or descriptive data might contribute to the normative inferences drawn by a moral community, but norms are not the direct result of merely naturalistic or descriptive analysis. Instead they are engineered, and, importantly, can be re-engineered. And while this kind of normativity indicates how a moral community values, it does not necessarily indicate what is valuable. To say health is normative on this view means that it is not reducible to a descriptive account. Instead, it is a constructed concept. Further, health is valuable insofar as a moral community picks it out as an operative concept.

The second layer of normativity is evaluative, in which norms express value judgements about the good or bad of a feature by how it is promoted or denied through norms. In this layer of normativity, norms are explicitly expressing not only that a concept is worth conceptualizing, but specifically what is valuable internal to the concept. Again, that something is valuable within a given context is not to say that it must be so. This kind of normativity, when applied to health for example, indicates that health is a concept according to which a moral community identifies value as per the first layer of normativity, and further that evaluative judgements are expressed by the content of the concept of health.

Sex and gender distinctions provide a quick illustration. Sex indicates descriptive anatomical features of a body (though this is not without some controversy). Gender, however, reflects the normative practices that society associates with being a particular sex (the first layer of normativity) and can contain embedded evaluative judgements about the value of features associated with various genders according to the second layer of normativity (that "woman" is negatively associated with being weak, or positively associated with being nurturing; that "man" is negatively associated with being aggressive, and positively associated with being authoritative; and the various ways being non-binary or queer are still marginalized identities reflects evaluative norms as well). Moreover, that gender has exploded as a concept to encompass a larger range of gender identities than a simple sex-distinction reflects the social construction and reconstruction of norms.

Barnes's analysis of disability parses out these two layers of normativity, with implications for accounts of health. We might say that organizing our world around a distinction between ability and disability already suggests a valuing around the category of disability as a distinction useful to convey meaning. Barnes shows that how we come to understand the contents of disability is normative. Although there are some biological details attached to it, what constitutes disability is a social product of a world in which certain features lead people to be less able to navigate that world.[56] This is the first layer of normativity: that disability is a product of a socially constructed definition, not a naturally or inherently occurring one.

For example: before the advent of eye glasses, being near or far sighted might have been a life-limiting condition. For those without access to eye glasses now, it may still be a disabling condition. However, in societies with ready access to corrective eye glasses, being near or far sighted is merely a feature of one's anatomy, rather than a disabling feature. Those who wear eye glasses in the United States currently are not valued less for wearing eye glasses; in many ways eye glasses have been embraced as a way to express individual style.[57] What counts as disability is a product of the social environment in which the concept disability is normatively constructed. On the Barnes account of disability, this view of normativity is not only accurate to capture the concept of disability, it is the most apt, and therefore preferred way, to conceptualize disability because it allows us to understand the ways in which we can reconstruct our social world to improve the lives of, and regard for, disabled people, including how we even identify people as disabled.[58]

The jump to the second, evaluative, layer of normativity in which norms entail value judgements of good or bad, is what Barnes would have us reject with regards to disability. Her mere-difference account says that there is nothing inherently bad (or good) about disability, though there are ways in which being disabled produces bad (and good) results for the disabled person, by virtue of the social world in which disability exists. So being near or far sighted without access to eye glasses might produce bad conditions for the person who lacks access: it makes her objectively worse-off, unless her given context has developed other ways to accommodate her limited vision. If her context were to accommodate people with limited vision, who did not or could not wear glasses, then perhaps she would be disabled, but not worse off in view of this disability. It is being in a context that cannot accommodate her need for eye glasses, and cannot accommodate her limited eye sight, that makes her both disabled in that given context, and also worse off.

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[56] Barnes.

[57] I don't think my point here is biased by being a life-long eye glasses wearer myself, but in the spirit of full disclosure, this example is informed by direct experience of wearing eye glasses.

[58] Barnes uses the phrase "disabled people" in this order on purpose, as a mere description that fits with this view of normativity as a mode of descriptively capturing mere difference, not as a pejorative term.

That disability is normative does not imply that disability is necessarily undesirable. It is merely one of the, albeit spurious, norms that we have created around disability through our social practices. Yet these practices can be revised to remove the value-judgement that accompanies the concept of disability. Disability can be normative and also value-neutral.[59] Recognizing the different ways the concept of disability is normative supports a better understanding of how the concept of health is also constructed, and, quite often, evaluative.

Daniels does not recognize these two layers of normativity that would allow norms to be socially constructed yet value-neutral. He claims that we can avoid a normative view of disease or pathology by showing that we do not consider all "unwanted" conditions to be disease, such as an unwanted pregnancy.[60] Additionally, some wanted conditions are, in fact, disease. Infertility, he charges, is a disease because it departs from species-typical functioning, according to which the assumed objective of biological functioning is to reproduce the organism. Infertility remains a disease even if some people prefer to be infertile, and even seek out procedures to render them unable to reproduce.[61] On Daniels's view, if someone never wanted to become a parent of biological children, took precautions to avoid pregnancy short of sterilization, and never discovered that for anatomical reasons she could not bear children, she would have a disease (albeit one that had no impact on her own life projects and goals, that is to say, no known impact on her equal opportunities. We might also say that it had no impact on her physical, mental or social well-being).

On the contrary, someone who has an "unwanted pregnancy" does not have a disease.[62] But she also does not have an illness. So although Daniels initially characterized a distinction between disease as a biological descriptor and illness as an evaluative descriptor, his example shows that not all bodily conditions that could interact with health care systems fall under the categories of illness or disease. Although someone seeking an abortion requires medical services and access to health care, this is neither in response to a disease, nor an illness. Daniels thinks we can draw a bright line between health care that treats disease (in which disease is separate from the characterization of a

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[59] Barnes.

[60] Daniels, *Just Health Care*, 30, Daniels, *Just Health*, 42.

[61] Daniels, *Just Health Care*, 30. Though it seems odd to say that a person who has a tubal ligation has caused disease in their body, especially if this procedure is to concord with their preferences around child-bearing, or if the procedure responds to other pathologies, such as conditions that would be worsened by becoming pregnant. In that case we would not tend to think they have caused disease by purposefully causing infertility in the body to treat a disease condition. Even when infertility is a side effect of another treatment (such as the side effect of chemotherapy treatments for cancer) it does not seem apt to characterize the infertility itself as a disease, though it is an unintended but foreseeable outcome of disease treatment.

[62] Ibid., 30.

condition as an "illness"), and health care that addresses other "social goals," one of which is unwanted pregnancy.[63] However, this line might not be as bright as he paints it to be. As he said, our biological goals are as social animals, which makes our health goals, to the extent that he takes health to be directly correlated to biology, to also be social goals. And when interacting with a health care system, the system must fit procedures like elective abortion into diagnostic codes, as it does with any treatment for a disease.

Daniels acknowledges that being purist about meeting only narrowly construed medical needs according to his disease/pathology and species-typical functioning paradigms can lead to further injustices, especially in reproductive cases when lack of access to bodily control, pregnancy prevention, or safe abortion can have other social and health impacts, especially for low-income women.[64] But situating his examples in a reproductive health services context raises other questions about the divide between normative and descriptive views of health, or the plausibility of a socially constructed and species-typical functioning dichotomy.

For example, not all "unwanted" pregnancies are unwanted for the same reasons, and Daniels's analysis overlooks the vast array of social, economic, and biological reasons someone might have for terminating a pregnancy. Some potential reasons for terminating a pregnancy only arise out of unique features of medical technology, which can test for particular disabling and disease conditions. The choices of what conditions to test for are informed by species-typical functioning views of health. And these biomedical technologies have the power to transform "wanted" pregnancies into "unwanted ones."

Perhaps he takes his phrase "unwanted pregnancy" to convey a pregnancy that is merely unplanned or inconvenient. But a person seeking to terminate a pregnancy might do so because she discovers that the pregnancy deviates from an account of species-typical functioning. Whether or not this is a valid reason to terminate a pregnancy is debated by disability rights and medicine scholars.[65] Overall, we might have good practical reasons to remain agnostic regarding right and

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[63] Ibid.

[64] Ibid., 32.

[65] See for example: Boardman, Felicity Kate. "The Expressivist Objection to Prenatal Testing: The Experiences of Families Living with Genetic Disease." *Social Science & Medicine* 107 (2014): 18-25. Edwards, Steven D. "Disability, Identity and the 'Expressivist Objection.'" *Journal of Medical Ethics* 30.4 (2004): 418-420. Kittay, Eva Feder. "On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with My Son," in *Prenatal Testing and Disability Rights,* edited by Erik Parens and Adrienne Asch. Washington, DC: Georgetown University Press, 2000. Parens, Erik and Adrienne Asch. "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations." *The Hastings Center Report* 29.5 (Sept/Oct

wrong reasons for terminating pregnancies, and good theoretical reasons to allow for plausible, plural sources for justifiable reasons for pregnancy termination in individual cases. As it specifically relates to Daniels's view of health, however, we might wonder how a species-typical account of health, and the practice of medicine itself, influences what information we seek, have access to, and the conclusions we draw from it. The practice and norms of medicine, I suggest, shape the contours of what is perceived to be species-typical functioning.

Because science, anatomy, and medical practice have identified technology to diagnose poor eye sight and correct it, imperfect eye sight is not regarded as a departure from species-typical functioning. Instead, medical science has allowed this condition to proliferate in ways it otherwise might not, were it not a correctable condition, and instead had implications for individual and species survival. The involvement of medicine in prescribing species-typical function is no less true in the reproductive examples Daniels offers. The practice of medicine, and embedded normative assumptions of health internal to them, inform his cases more than he recognizes.

Similarly, the practices of medicine shape the parameters of what kinds of functioning is species-typical, and what kinds of departures from species-typical are worthwhile to treat. The advent of neonatal intensive care, for example, illustrates the ways in which medicine shapes what is typical by shaping what is valued and perceived to be valuable. In the early days of neonatal technology, decisions were often made about whether to extend the life of a precarious newborn based on assumptions about their future cognitive capacity, and whether or not they would have "normal" intellectual function, without fully recognizing that choosing who does and does not receive care, and therefore who lives and who does not, shapes the range of what is "normal."[66]

Let's look more closely at Daniels's example of infertility. For a person who never wanted to bear children and also never knew she couldn't, the practice of medicine and the ability to asses reproductive functioning might lead to a discovery of so-called disease. Our imagined disinterested-in-child-bearing person goes for a routine gynecological exam as part of a standard package of medical care, and learns that she is likely infertile. Further testing and diagnostics could definitively diagnose this "disease." Yet this is not information she sought out, and it has no bearing on her particular fair share of opportunity, given her disinterest in being pregnant. She likely would not benefit from further testing to confirm a diagnosis. In this instance, the WHO definition of health

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1999): Special Supplement. Sparrow, Robert. "Imposing Genetic Diversity." *The American Journal of Bioethics* 15.6 (2015): 2-10.

[66] See Anspach, *Deciding Who Lives,* especially the introduction and chapter 1.

might provide this person with a better functional definition of health, because her well-being is not influenced by a notion of "species-typical functioning" that renders her diseased.

Now if we imagine a person got (species-typically) pregnant, and let's assume intended to, medicine also can reveal to her a number of features of her pregnancy that it could not less than half a century ago. In this case we will imagine that medical technology indicates the fetus has chromosomal anomalies resulting in likely physical and cognitive limitations. The fetus will not achieve species-typical functioning of the kind Daniels envisions. Let's imagine the pregnant person understands this departure from species-typical functioning to mean her potential child would not have a fair share of opportunity, and would not be a "normal, active, and fully cooperating" member of society "over the course of a complete life"[67] in the Rawlsian sense of social cooperation that underscores Daniels's view of health care. For these reasons, which the pregnant person sees as entirely justified on an account of species-typical functioning, she no longer wants to remain pregnant, and decides to terminate the pregnancy.

In this case, species-typical views of health transform her pregnancy into an unwanted one. At the same time, this "unwanted" pregnancy reinforces a putatively descriptive view of species-typical function, by eliminating an opportunity for a person who departs from this account of "species-typical" to exist. The choice to terminate the pregnancy is not merely a social choice, though it is also a social choice. The pregnant person is making a determination based on attributions of atypical species function; she is also making an assessment about what departures from species-typical function mean in her given social context. The switch from a wanted to an unwanted pregnancy occurs because of a perceived standard for species-typical functioning, produced in part by the practice of medicine that has developed the testing and diagnostic tools to pick out certain features of a-typical species functioning as worthy of prenatal assessment, in part to allow for the potential termination of pregnancies of so-called a-typical fetuses, presumably in order to limit overall incidences of live births that depart from species-typical function.[68]

As an example, at the end of the 20th century fetuses and infants diagnosed with Trisomy 18 were classified as departing from species-typical functioning in ways that were often described as

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[67] Rawls, John. "Social Unity and the Primary Goods" in *Utilitarianism and Beyond* edited by Amartya Sen and Bernard Williams. Paris: Cambridge University Press Editions de la Maison des Sciences de l'Homme, 1982: 159-185, 168.

[68] Although contested in the literature, arguably the fact of picking out and testing for these atypical features makes an evaluative judgement that species typical functioning is more valuable than atypical functioning, and also what kinds of functioning, or lack thereof, is atypical. See references in note 63.

"incompatible with life."[69] The "devastating" effects of the additional 18th chromosome these fetuses had led to "one of the few areas of high moral certitude" about the correct course of action to withhold life-saving treatment from babies born with Trisomy 18.[70] Yet the practice of medicine to withhold life-saving treatments (which are readily available to, and even imposed upon fetuses and infants with other diagnoses) from fetuses and infants with this particular diagnosis contributes to the condition being non-survivable. These fetuses could only have a chance at surviving if given the chance to survive that medicine can make possible for fetuses with other conditions.

We could equally say that other conditions with which babies are born and in acute need of life-sustaining treatment would, without the advent of medical technology, be incompatible with life. Infants needing to be resuscitated at birth would not survive save for the availability of medical intervention. It is the medical practice itself that allocates the technology of resuscitation to those it understands to have lives worth saving, or lives worth living. In part, this may be a reflection of the perceived likelihood of success of an intervention.

But the notion of success if evaluative: it might not be viewed as a success to sustain a life that will be lived with serious cognitive impairment.[71] Changing views so far in the first quarter of the 21st century are producing new attitudes toward automatically terminating pregnancies or withholding life-sustaining treatments because of likely physical or cognitive impairment, or due to perceptions about "quality of life." As a result, Trisomy 18 is not automatically considered a lethal condition. Instances where pregnancies are continued and newborns receive necessary life-sustaining treatment after delivery have led to the discovery that in some cases of the condition, "long-term survival is possible."[72]

The biomedical paradigm of health that rests on an account of species-typical functioning at the same time makes inferences about, and sets the parameters for, what is species-typical for the human species. It assumes that science can "examine what is observable and measurable,"[73] and then

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[69] Andrews, Sasha E., Ann G. Downey, David Scott Showalter, Heather Fitzgerald, Vivian P. Showalter, John C. Carey, and Peter Hulac. "Shared Decision Making and the Pathways Approach in the Prenatal and Postnatal Management of the Trisomy 13 and Trisomy 18 Syndromes" in *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 172.3 (2016): 257-263, 261.

[70] Anspach, 149.

[71] For example, Rene Anspach reports clinicians in a NICU in the early 1990s seeing no point to offering life support for a baby that would not be "normal" or would be "slow." See Anspach, *Deciding Who Lives.*

[72] Russo, Francesca M., Elisa Pozzi, Maria Verderio, Davide P. Bernasconi, Valentina Giardini, Carla Colombo, Silvia Maitz, and Patrizia Vergani. "Parental Counseling in Trisomy 18: Novel Insights in Prenatal Features and Postnatal Survival." *American Journal of Medical Genetics Part A* 170.2 (2016): 329-336, 335.

[73] Yuill, Chris, Iain Crinson, and Eilidh Duncan. *Key Concepts in Health Studies*. London: Sage, 2010, 8.

draw accurate conclusions based on these observations. These inferences become scientific fact. When observing the human species, inferences are drawn about the optimal flourishing of the species. Such inferences project, as much as reflect, assumptions about the goals for the species, including commitments to the survival of the species, and, related to survival of the species, reproduction. They also suggest that what is observed to occur in nature are what ought to occur. They imply that was we understand to be natural is equivalent to what is good and right.

Yet the inferences drawn about the goal of, or best route to, survival of the species, for example, are a form of "knowledge construction." They do not merely draw upon fixed empirical or biological fact, but also include implicit "cultural and social assumptions," in terms of what is interpreted as biological fact.[74] The norms of medicine, and the capacities and technologies medicine has developed, produce the possibility to make certain kinds of health assessments and decisions.

What medicine can know and do is context-dependent, contingent on the time and place in which it is practiced. What becomes typical of the species may also therefore be context dependent, contingent on time and place. Social structures, including the social structure of medicine, do not merely reveal empirical or biological fact, they actively shape the choices of what kinds of facts to pursue, how to interpret them, and what kind of research and medical agenda to promote.[75]

Moreover, as I have already suggested, medical technology and practice alters possibilities for the range of normal species function.[76] To return to the eyesight example: without medical technology those of us who wear glasses would likely not survive to reproduce future generations with limited eye sight. Technology that allows to correct vision makes imperfect vision entirely species-typical. Daniels notes that health care decisions require a thinner veil of ignorance, because we need to know details about the context in which health care decisions are being made. This includes details about what capacities and resources are available, which include available medical technologies.[77]

But we can extend Daniels's point to see that what is included in the scope of species-typical function is contingent upon capacities and resources available. Ideological critique and the sociology of knowledge recognize that "ideas are shaped by the social settings in which they develop."[78] Similarly, the idea of health as species-typical functioning is shaped by, and a product of, a social

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[74] Yuill et al, 7.

[75] Anspach, 52.

[76] Weinstock, 3.

[77] Daniels, *Just Health Care*, 47.

[78] Anspach, 57.

setting that recognizes and promotes certain features as species-typical, including medical practices responsive to a vision of species-typical functioning. Normal functioning is both normative and plastic:[79] it can be redefined as contexts evolve.

Daniels acknowledges differences in social setting, but relates these to the types of opportunities that are promoted or required in a given cultural context, not to a different view of what is species-typical depending on context. He observes, for example, that being dyslexic might not be a set-back to opportunity in a culture that does not rely on written language. Yet he takes dyslexia to be a pathology whether or not it is essential for success in one's given context. In this way he suggests that health is important to opportunity, but which health needs are promoted are context-dependent. Yet the very idea that one cultural context does not engage a written language in which dyslexia would be a set-back to opportunity runs counter to the idea that there can be a single observable and deducible species-typical function that is not culturally or context dependent.

Daniels anticipates a related, and potentially circular, worry: that normal functioning is the standard for health care, but is also determined by health care access (which is distinct from what I have been arguing, that it is determined by health care practice). In response he asserts that access to health care "will in general affect the **distribution** of shares of the normal opportunity range, not the range itself."[80] Yet the case of prenatal fetal testing suggests that in some instances perceived "normal" functioning provides a standard for health care, and health care access influences the range of "normal" functioning and opportunity. It is only through an encounter with health care systems that a pregnant person can test and select for traits perceived to be "normal" over those that are viewed as "disabled." Even if "disabled" is a descriptive term when applied to a fetus, the choice to treat or terminate it, to make life and medical access available to it, or to withhold from it one or both of those things, is normative in the sense that it enacts and reinforces social and health norms.

Daniels's case of unwanted pregnancy in many ways suggest that the dividing line between social constructs and health is much more permeable than he acknowledges. My worry is not that standards of health care determine health care access: this would simply mean that health care values inform health care access, and then we could ask important questions about what constitutes health care (as opposed to health), which I say more about in this chapter and the next. Instead, a specious account of health informs health care practice, and health care practices partially construct what constitutes health. That health and health care are mutually responsive to one another is not what is

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[79] Weinstock, 3.

[80] Daniels, *Just Health Care*, 55.

at issue. What is flawed is an embedded assumption that the concept of health is empirically and externally fixed instead of responsive to constructed norms and practices of health care.

A commitment to a species-typical view of health might lead to another question about how our imagined pregnant person with a fetal anomaly should proceed according. On the Daniels/species-typical account of health, is a fetus that will never develop into a "species-typical" functioning person an apt recipient of health care, if the purpose of health care is to promote, preserve, or restore such species-typical functioning? Would it be not only morally acceptable to terminate this pregnancy in light of Daniels's view, but in some ways morally required to do so in order to meet the demands of health care justice grounded in a species-typical definition of health as necessary for opportunity?[81]

Feminist and disability scholars give us reason to be wary of a theory that produces this outcome.[82] In the next chapter I expand a theory of health care, and address in more detail the view Daniels takes of social, rather than strictly medical, support services to those who, in his vocabulary, cannot be restored to normal functioning. Importantly he sees "medical services and social support services that meet health-care needs have the same rational and are equally important," though he indicates that "for various reasons" related to the profitability and prestige of medicine, "our society has taken only slow and halting steps to meet the health-care needs of those with permanent

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[81] There is a robust debate since at least the advent of intensive neonatal technology between a range of views arguing for preservation of all life at all costs to permissible infanticide in light of severe physical or mental disability due to the inferred quality of life of people with such conditions, or the burdens on society and families that arise due to the costs and care required for such persons. On the side of preserving life see: Kluge, EHW. "The Euthanasia of Radically Defective Neonates: Some Statutory Considerations." *Dalhousie LJ* 6 (1980): 229-257; Kluge, EHW. "Infanticide as the Murder of Persons," in *Infanticide and the Value of Life*, edited by Marvin Kohl. Prometheus Books, 1978; Ramsey, Paul. *Ethics at the edges of life: Medical and legal intersections*. Vol. 358. Yale University Press, 1978. On the other side of the debate, Peter Singer might be one of the most prominent voices in print. See: Singer, Peter. "Unsanctifying Human Life" in *Ethical Issues Relating to Life and Death,* edited by John Ladd. New York: Oxford University Press, 1979; Kuhse, Helga, Peter Singer, and Peter Singer. *Should the Baby Live? The Problem of Handicapped Infants*. Oxford: Oxford University Press, 1985; Singer, Peter. "A Report from Australia: Which Babies are Too Expensive to Treat?" *Bioethics* 1.3 (1987): 275-283. And for an analysis of the debate itself, see: Long, Thomas A. "Infanticide for Handicapped Infants: Sometimes It's a Metaphysical Dispute." *Journal of Medical Ethics* 14.2 (1988): 79-81.

[82] Barnes, Kittay, and Anita Silvers offer a non-exhaustive sample of the literature. In addition to Barnes and Kittay texts previously noted, see also Silvers, Anita. "From the Crooked Timber of Humanity, Beautiful Things Can Be Made", in *Beauty Matters: New Theories of Beauty*, edited by P. Brand. Bloomington: Indiana University Press, 2000, 197–223; Silvers, Anita. "On the Possibility and Desirability of Constructing a Neutral Conception of Disability." *Theoretical Medicine and Bioethics* 24.6 (2003): 471–487; and Silvers, Anita. "The Right Not to Be Normal as the Essence of Freedom." *Journal of Evolution and Technology* 17 (2008): 78–84.

disabilities. These are matters of justice, not charity."[83] What I think this gets right is the emphasis on justice, not charity, and that medical and non-medical services are all equally part of health care.

What I think he gets wrong, though, is committing to a narrow view of social support as running parallel to, rather than integrated into, health care. For Daniels, only at the point at which medicine can no longer achieve its objective to restore so-called species-typical function are social support services for health care relevant, suggesting that he wishes to maintain what I take to be a false dichotomy between the medical/biological, and the social/cultural. Certainly, Daniels sees the importance of the "social determinants of health," especially in his more recent writing. But he seems to characterize the social determinants as parallel to health care. He acknowledges that health care itself plays a minimal role in health outcomes relative to the social determinants of health, suggesting a view of health care as distinct from other social goods and institutions.

But even if social determinants of health have a greater impact on overall health outcomes than access to health care, social determinants of health like economic or social status also influence access to health care. And if these social features are assumed run parallel to health care, then serious exclusions from health care access will persist, in addition to worse health outcomes. Minimal social supports we could imagine for overall "healthy" people might include: having time off for or transportation to preventative health appointments; having access to a local clinic in order to be able to vaccinate your children against preventable disease; education about health and nutrition along with subsidies to support accessing health care and nutritional resources.

As people become (possibly only temporarily) less "healthy," but still able to be restored to putative species-typical functioning, they may be particularly reliant on social supports as part of their medical care. For example, someone undergoing chemotherapy treatments for cancer, would need reliable and consistent transportation to her appointments and infusions, in order to access medical care interested in supporting and restoring her species-typical functioning.

Daniels does imagine some situations in which social support services are required for justice. But he takes a minimal view of health care justice and health care institutions, according to which "health-care institutions have the limited function of maintaining normal species functioning: they eliminate individual differences due only to disease or disability."[84] Yet if we recognize disability as at least partially socially constructed, as contemporary disability scholarship persuasively does, this problematizes a tight connection between species-typical functioning and the differences caused by

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[83] Daniels, *Just Health Care,* 85.
[84] Ibid., 53.

disability. What is species-typical is what we accommodate as typical within our social context. If we construct a world of ramps in addition to stairs, then using a mobility aid no longer falls outside of typical species functioning, because it does not impede any typical species activity.

The easily imaginable case of the wanted and then unwanted pregnancy due to a detected fetal anomaly is fraught for many reasons: whether this is a right reason to not want a pregnancy; whether "wanted" is the right way to think about pregnancy at all;[85] and whether disability is atypical species functioning only in a descriptive sense, or also in a normative sense. If medicine can prevent the occurrence of a so-called species atypical fetus from resulting in a live birth, then is that the accurate application of health care justice when motivated by a species-typical view of health?

Or, if medicine can detect these departures from species-typical function, is it the role of health care justice to abandon a strong commitment to species-typical function in so far as health care justice obligates social supports be in place to meet the needs of the future parents and child in this situation? I think Daniels wants to endorse the latter view, yet his theory committed to health as species-typical function underpinning an account of health care justice does not achieve this goal. Furthermore, it sets up an unnecessarily narrow view of health care, according to which social supports run parallel to health care rather than be central to the provision of just health care.

Rawls's ideal cooperating society members are a starting point to theorize ideal justice, as Daniels says, in order to then turn to the difficult, non-ideal cases.[86] Daniels takes this to mean that ideal theory does not require a theory of health care because no one would get sick.[87] Yet Rawls's ideal member of society will be a "normal, active and fully cooperating member… over the course of a complete life."[88] A complete life spans from birth to death. This means we need to be sensitive to not only the moral development of future cooperating members of society during their childhood, but also to the foreseeable decline of such cooperative society members.

Feminist scholarship challenges Rawls's ideal theory, and notion of full social cooperation, especially through the lens of disability. For example, Eva Feder Kittay charges that all those "we wish to include" as members of a just society "may not fit the model of the social cooperator

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[85] Watt, Helen. *The Ethics of Pregnancy, Abortion and Childbirth: Exploring Moral Choices in Childbearing.* New York: Routledge, 2016. I disagree with most of Watts's approach and ethics of pregnancy, abortion, and childbirth, which is largely influenced by natural law theory; however she proposes a useful challenge to the language of desire when it comes to pregnancy.

[86] Daniels, *Just Health Care,* 43.

[87] Ibid.

[88] Rawls, John. *Justice as Fairness: A Restatement.* Edited by Erin Kelly. Cambridge, MA: Harvard University Press, 2001, 174.

without a lot of distortion, if at all." However, she does not abandon the "notion of fair terms," instead she proposes an alternative account of justice in which "justice provides the fair terms of social life given our mutual and inevitable dependency and our inextricable interdependency."[89] I say more about models of justice centered on dependency in the next chapter when I analyze the concept of care in health care.

Our biological goals are in part a product of our social nature, as Daniels acknowledges. This means that the ways we structure our society, and how we regard the justice due to members of our society, is not merely a biological enterprise. It is also a social one. And furthermore, it is possible to imagine differently than the ideal model of socially cooperative members Daniels inherits from Rawls. Kittay (and others) have offered alternatives in which those who count as a member of society to whom justice is due is not indexed to particular capacities. Instead, acknowledging capacities might lead the society to recognize what special rights one has who lacks particular capacities, but also what special duties one owes, by virtue of having certain capacities, and that such recognition of special rights and duties is as a matter of justice.

Daniels allows for there to be other reasons health care could be special outside of species-typical functioning. These include: the solidarity of care; fragility of life; minimizing suffering; or improving quality of life. Yet he sees these as plural contributions to health care, not grounding reasons for a right to it.[90] Health as defined by species-typical function and fair equality of opportunity, on the other hand, engage a unique argument for health care justice.[91] This is true even if health might not be as special as Daniels initially thought, a fact he acknowledges.

As already touched on, research in the early 21st century suggest that health status is only partially determined by health care access. The social determinants of health (nutrition, environment, shelter, income, social and political standing, environment) all weigh heavily on morbidity and mortality.[92] Access to health care has relatively minimal influence on aggregate health outcomes[93] (though it would have enormous influence on individual health outcomes: statistically speaking,

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[89] Kittay, "Centering Justice," 286. Also see Iris Young for a broader critique of Rawlsian ideal theory: Young, Iris Marion. *Justice and the Politics of Difference.* Princeton: Princeton University Press, 1990.

[90] Daniels, *Just Health Care,* 49.

[91] Ibid., 50.

[92] Daniels *Just Health*; Commission on Social Determinants of Health. "Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health: Final report of the Commission on Social Determinants of Health." World Health Organization: Geneva, 2008.

[93] Daniels, *Just Health,* 80. Daniels notes that even in contexts of universal access to health care, disparities in health persist according to socio-economic status, suggesting that it is the status, not the access, that is doing more of the heavy lifting to produce health outcomes.

access to health care might not impact overall occurrences of a highly treatable but otherwise deadly form of cancer, but in an individual occurrence, access to health care is the difference between access to life-saving treatment, and certain death from cancer).

Some challenge Daniels's account of the just health care in light of these findings.[94] If health care is no longer so important for health, but (species-typical) health protects fair equality of opportunity, then what is so special about health care after all? It looks like many other goods need to be supported to produce health, and promote fair equality of opportunity. Daniels invites the opposition, but maintains that health care remains important as part of a larger package of social justice initiatives that also address social determinants of health, because health is of central importance.

I think we should challenge Daniels not for defending health care as important, but for his adherence to a narrow view of health the primary justification for supporting health care and other social justice systems. We should challenge his justification for health care not merely because other things contribute to health, although they do. We should challenge his account because it hinges on a view of health as species-typical function, which cannot truly respond to the demands of justice. It leaves out those who ought to be recipients of care. They ought to receive care especially because they do not conform to a normative view of species-typical function. Yet they are also marginalized within this account of care for being putatively species a-typical. Justice ought to demand that differences requiring particular kinds of care be included in, not left out of the fabric of society.

Disability theory, such as that of Barnes, recasts disability as a social construct that is value-neutral to the biological facts of disability, and opens up a fruitful way to not only reconceptualize disability, but to also reconceptualize ability and health care. As I have stressed, Daniels only addresses social services as a component of just health care when they respond to chronic illness or disability.[95] Yet challenging species-typical constructs of chronic illness or disability also challenges who we take to be apt recipients of social supports and therefore also of just health care. In the final section of this chapter I consider a different way to think about a distinction between health and health care.

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[94] See for example Sreenivasan, Gopal, "Human Right to Health? Some Inconclusive Skepticism." *Aristotelian Society: Supplementary* 86 (2012): 239-265 and Wilson, James. "Not so special after all? Daniels and the social determinants of health." *Journal of Medical Ethics* 35.1 (2009): 3-6.

[95] Daniels, *Just Health Care,* ix, 85.

I argue for an expanded view of health care which generates expanded obligations for health care justice. My account does not draw the same distinctions between health care justice and social-justice-in-the-service-of-health care that Daniels's view requires. It also is more actionable than overly broad definitions of health as general well-being that plague the WHO account of health, and limits its ability to motivate an account of health care justice. In the next chapter I expand on the concept of care, and propose an account of health care that I contend meets the demands of a caring justice in ways that health care justice grounded in problematic concepts of health cannot.

Health As an Ideal

For Daniels, the applied philosopher needs to know her limits between her theory and the applied context, and recognize that her theory is going to be limited in its ability to apply to the actual cases that arise. Daniels takes this to be an invitation for ideal theory to engage with non-ideal practice.[96] However, we can also recognize the limited usefulness of an ideal theory that does not produce a practicable framework. It is one thing to say that the results of an ideal theory in practice will be hard, or will require radical change. It is another to say that the theory cannot accommodate the case, or the case cannot fit with the theory.

Accepting this invitation from Daniels to engage the ideal with the non-ideal, I contend that we should adopt theoretical models of health and health care that are compatible with disability and feminist theory. Disability scholarship particularly helps us rethink health, and the organizational assumptions of society. Feminist scholarship acutely helps us rethink care, and the organizational assumptions of moral communities. And disability and feminist scholarship are in close conversation with, and are mutually informed by, each other such that they are in dialogue together.

Furthermore, I take the health care context to be not only an occasion to apply ethics, but also an invitation to reimagine our moral commitments and constructs in order to meet the questions of justice that medical and health innovation, and knowledge, challenge us to consider as a moral community. In the remainder of this chapter I propose a distinction in kind between health and health care for the purposes of health care justice.

As discussed, Daniels focuses on an account of health care justice committed to a species-typical functioning definition of health. Accordingly, Daniels characterizes the role of "health-care institutions" as limited to "maintaining normal species functioning: they eliminate individual

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[96] Ibid., 229.

differences due only to disease or disability."[97] Yet this is clearly not true in practice, and I would maintain that we should not make it true. Health care systems may not be able to maintain an ideal standard of normal species functioning as they have constructed it. And if they cannot maintain this standard, they do not and should not abandon obligations to provide health care.[98]

Daniels grants that social support services only or mainly enter the scene when responding to chronic illness or disability – when there is a clear departure from supposed species-typical functioning. I have already suggested, and will continue to argue in the next chapter, that this is far too narrow a view of when and why social support services ought to be included in the concept of health care. Here I wish to underscore that the addition of social support services is not only at the subtraction of medical care, nor is medical treatment or social support a non-inclusive disjunction.

Yet an account that views the primary role of health institutions as to "maintain normal species functioning" cannot make sense of what to do when an irreversible departure from species-typical functioning occurs. Not only does a species-typical definition of health fail to produce justice when it motivates a theory of health care justice. It also yields an account of what health care is that appears to be at odds with our practices of, and expectations for, health care. Our expectations for health care might go too far, and our practices do not go far enough. Abandoning health as the motivating concept for health care justice, and establishing important distinctions about the nature of the concept of health, and the nature of the concept of health care, can move expectations and practices around health care closer together, and toward a theory of health care justice.

Both health as complete well-being according to the WHO definition, and health as species-typical functioning according to the biomedical model, set up health as an ideal. While the content of each ideal differs, it is helpful to recognize that they share the property of being aspirational. Callahan is likely correct in observing that "people will continue to die of disease for a long time to come, probably forever."[99] Thus complete health, according to a WHO definition, cannot be maintained across an entire lifespan, at least as biology currently constrains us through inevitable decay and death. Setting up the expectation of such a goal is a losing proposition. And it is certainly one to which we cannot make a rights claim, which will be the preoccupation of later chapters.

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[97] Ibid., 54.

[98] I want to note here that by suggesting there are obligations to provide health care is not equivalent to suggesting there are necessarily obligations to provide medical treatment. There are plenty of instances in which medicine cannot restore or maintain someone's biological functioning and it is appropriate to discontinue, or not offer, medical intervention and treatment. The point here and throughout is that health care is more than mere medical care and health care is not identical to medical treatment.

[99] Callahan, 80.

A defender of the WHO definition of health might respond that by defining health as more than "merely the absence of disease or infirmity" does not promise the absence of disease or infirmity. Put differently: absence of disease or infirmity is neither necessary nor sufficient for health. This looks like a generous, and possibly misleading, reading of the definition. By saying health is "not merely" the absence of disease, I take it that this is a necessary, but not sufficient, component of health.

Part of the problem, however, is that it is reasonable to imagine someone could live with a chronic or serious infirmity, and nonetheless have a high level of well-being, and even, subjectively, consider herself healthy. We could think that someone who lives with diabetes, say, and has a very healthy life with a high level of well-being, in part because of the managed care of her disease. Part of her well-being and health is achieved through the provision of health care, which is likely more than mere medical care. This care directly treats her pathology, improves her vision of subjective well-being, and minimizes suffering, especially unnecessary suffering.

Although they take different approaches, the WHO definition of health and the ICESCR highest attainable standard of health standard share several features that render them problematic targets for defining a clear claim-right, in part because they do not acknowledge a distinction that Callahan describes as a difference "between health as a norm and as an ideal."[100] Health as complete well-being, and even a highest attainable standard of health, are left too vague to pick out clear, attributable, and enforceable rights claims. Daniels recognizes that discourse of a right to health is intuitive, but also problematic, and therefore focuses on a right to fair opportunity, of which health is a necessary component. But centering health in his account, even with his starkly different definition of health, nonetheless requires an ideal notion of health to do too much work to produce a framework for a normative account of health care justice. "Health" and "health care" share the term "health," but they do not need to share the same conceptual structure or purpose.

On another view, "health" functions as a political concept in so far as it is defined within political contexts that identify and prioritize what are seen as important or relevant health issues.[101] Health care, then, is a reflection of what matters to a moral community in terms of how it values and conceptualizes health, and the priorities it sets for health care in accordance with these values and priorities.[102]

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[100] Ibid., 85.
[101] Weinstock, 5.
[102] Ibid., 6.

Such an account takes health to be a social and political norm, and health care an application of that norm. Though even a political account of health priorities that entails values and practices of health care does not necessarily lead to rights claims to either health or health care. It does not follow, for example, that because (a kind of) health is good there is a need for health (or health care) and therefore a right to health (or health care) that produces special claims on health (or health care).[103]

Health inequalities will persist even in the most just society, whether we take a broad or narrow view of health.[104] The fair distribution of health is an unachievable objective, but perfect realizability of fairness is not the criterion of my critique. It is fine to strive toward fairness, recognizing that it will always be incomplete and imperfect. Health will also always be incomplete and imperfect: it will not be realized by many of us some of the time, and not by any of us all of the time.

My greater worry is that health itself is an ideal. Moreover, if we accept what I think is reasonable pluralism about health, then it is unclear what it is we would be attempting to distribute by distributing "health" fairly. We may not be able to arrive at an overlapping consensus of what kind of health we are aiming to allocate.

Yet if we disentangle health care from a commitment to any particular view of health, whether an ideal or normative one, we can move health care toward more just practices, including ones that entail rights claims, and responsibilities to respond to rights claims. For the purposes of this project, I will avoid a normative definition of health (though I endorse that defining health is a normative enterprise). I offer a tripartite distinction between health, healthy, and health care. Ultimately, by the end of the next chapter, I am going to make a strong case for a particular normative account of health care.

On my approach, health is primarily an ideal, or an aspiration. As such, health can stand in for a variety of beliefs and values that could fill in a definition of health. It also permits what I think is a reasonable pluralism about the concept of health. Additionally, regarding health as an aspirational concept keeps health from becoming a fixed notion. This allows the possibility that health norms vary depending on culture and context, and certainly evolve in parallel to medical innovation and capability. Yet because health is an aspiration, it is not something to which anyone

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[103] Ibid.

[104] Ibid.

can have a claim-right. And even if there were claim-rights to "health," it is unclear to whom the correlative duties would accrue.

The concept of "healthy" is a state of being that reflects a normative notion of health as well as the subjective experience of health, with reference to a given ideal of health. If health is an ideal concept, then to describe something as "healthy" is a context-specific application of the ideal. "Healthy" therefore reflects normative applications of the aspirational concept of health.

"Health care," can support the striving toward ideals of health. But most central to health care is that it is a concept grounded in the social practices of caring. Health care is a relational practice, not an abstract ideal. Health care is only a normative concept. While health care practices may reflect the abstract ideals available within a moral community, health care is always already enmeshed in social practice and cannot be separated from its social and political context.

Put differently, health care requires, and only arises as a product of, social structures and realities of caring relationships. Such caring relationships may be between individuals or between individuals and institutions. Furthermore, that health care is a social enterprise is what makes health care special. Instead of focusing on what makes health special to motivate an account of justice, recognizing how health care is special is what produces rights to and responsibilities for health care. Health care as a practice also ought to reflect, as well as generate, more just social relations through what I call in the next chapter "care justice."

Even if we have pluralist conceptions of health and being healthy, health care can converge as an overlapping consensus because it is different in kind from health, rather than merely the application of a concept of health. For this reason, it is appropriate to focus on a right to health care as a relational practice of care. This account can succeed where frameworks for rights to health (which I discuss in chapter four) and accounts of health care justice motivated by health (which I discussed in this chapter) fail.

Anticipating an objection to my view that being pluralist about ideal conceptions of health is a reason to reject a right to health and to support a right to health care, one might say that my view does not yield a stronger theoretical position: pluralism about health will simply result in plural, and conflicting, approaches to what is good in health care. To this critique I have two replies. One is that I accept some reasonable pluralism about health care, in addition to pluralism about health. But this leads to my second reply, which is that because health and health care are different in kind, I understand something different to be at stake in health care justice than merely producing health, however you fill in the content of health. Given this difference in kind, I think that we can arrive at some shared features of the value and practice of health care, that can accommodate pluralist iterations of it, and that these shared values and practices will respond to health care justice.

Pluralism about health care is a feature, and not a bug, of my view. Furthermore, a right to health care can more easily accommodate pluralism than a right to health can. A right to health care places central importance on the role of care and makes possible that variable types and levels of care may be necessary based on the individual or her context. Health care starts from where a person or population is, with the objective to meet them there and to care appropriately in response to their needs. A right to health, on the other hand, either assumes a monolithic (but arguable) standard of health, or it produces a debate as to the ideal and normative content of health.

The central importance of care, and the intrinsically relational nature of care, provide a unique standpoint for grounding health care justice. Its objective is not to produce ideally healthy individuals and populations, nor to render all beings in optimal ideal health. Instead, it takes a more moderate view that recognizes some embodied suffering is inherent to human existence, if at no other point than at the moment of whatever causes death. And it also takes a more radical view that there are tools available within the practice of health care to attend to, address, and assuage such suffering. As I argue in the next chapter, this is a radical stance in that it is a much more demanding account of what ought to be included within the concept of health care to bring it in line with justice. But it is also a much more achievable program of how a moral community can responsively and collaboratively meet justice demands of care.

An expanded notion of health care that understands health care as necessarily comprising a variety of types of care to reduce suffering and support pluralist health aspirations also guards against another danger in focusing on health instead of health care: that of construing health as an overly individualistic enterprise. As I have said, health care is necessarily relational. While there can be individual pursuits that contribute to one's own health care, the idea of care is caring for someone, both for the self and others. A focus on health places too great an emphasis on individual health, at the risk of holding individuals uniquely responsible for their health shortcomings, or mere differences of health status.

Creating pressures on individuals to be independently responsible for an ideal level of health does not account for context, constraints, and realities, and at the same time it overlooks social engagement, opportunities or restrictions. This does an injustice to individuals, rather than promote justice. That the practice of health care is always already enmeshed in, and a reflection of, our moral communities is both why and how health care is the appropriate target of rights. The relational nature of care has implications for who has rights claims for health care, and who is responsible for responding to these claims. I elaborate on this in the chapters to come.

In the next chapter I further explore ethics of care, and a possibility for what I am calling "care justice," that I argue is achieved through an expanded definition of health care. I also fill in the content of this expanded concept of health care. The following chapters move to rights frameworks and specifically rights to health care frameworks. I consider how there could be enforceable claim-rights to health care, including my expanded concept of health care.

Finally, in the final chapters I propose what kind of moral community could be responsible for this expanded account of health care. There I argue for a complicity framework in which individuals are accountable for, and as members of, their moral community, with duties to address the claim-rights of their fellow community members. This includes claim-rights to an expanded concept of health care. The framework for rights and responsibilities I build, while occasioned by the case of health care justice, is not only the applied product of, but can also inform, a broader theory of moral community and responsibility.

II

The Care in Health Care

In this chapter I turn to the concept of care. Care ethics introduced a challenge to traditional accounts of justice by suggesting that virtues and practices of care were largely left out of the public realm, and specifically left out of questions of justice. However, the insights of care ethics also created a new dualism between justice or care, or a tension between the two that requires reconciliation. Virginia Held has suggested that care is necessarily prior to justice.[1] In the view I propose, neither care nor justice is prior; both can be produced through practices of justice enacted through care. Though not every instance of justice is an act of care and not all care is the enactment of justice, I argue that moral communities ought to co-construct justice and care conjointly.[2]

Building on the feminist scholarship that deconstructs gendered readings of justice and care, male and female, and public and private, I offer a view of care as a practice that enacts and responds to justice. This kind of care justice arises within and among the kinds of moral communities Margaret Urban Walker has described as expressive-collaborative.[3] Furthermore, I take this view of care justice to be an instructive feature of how moral communities are formed and sustained. In this way, I understand the health care context not only as an occasion to apply ethics, but as an invitation to reimagine our moral commitments and constructs. This moral reimagining responds to new questions of justice, occasioned by new medical and health innovation, and to the unique histories and practices of our existing social and political communities. Health care is not merely an application of an ethic, or micro-instantiation of a more macro moral community. The practices of health care require us to reflect upon and reconsider the grounding of our moral community in theory and practice.

Finally, I close this chapter by providing my account of an expanded definition of health care. Health care is necessarily relational. It places us in relation to other individuals and institutions. Part of the value of health care is that it engages us as a member of a community. I argue that the scope and definition of health care, and the rights to and responsibilities for it, are collaboratively

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[1] Held, Virginia. *The Ethics of Care.* New York: Oxford University Press, 2006, 17.

[2] While I will talk generally about moral communities in this chapter, I give a full account of the nature of moral communities tapped to engage such practices of care and justice in the final chapters.

[3] Walker, *Moral Understandings.*

produced and enacted in community. This view does not require a descriptive or normative definition of health, although it can accommodate plural normative views of health. Following on the previous chapter, my account allows for health to be an aspirational or ideal concept, while health care is an action-oriented concept.

My account of health care defines it as an expressive-communicative enterprise that encompasses more than mere medical care. Health care can also include, but is not limited to, social, economic, or political features as part of, not parallel too, health care. This last point is in line with current research into the social determinants of health, which are really social, economic, political and environmental (though my program is not prescriptive about what health is and remains pluralist regarding health). Yet my approach is distinct from primarily addressing the social determinants of health as matters of justice. As already argued, I take this to focus too greatly on health, while my focus is on the relational provision of health care.

While my approach to health care greatly expands its scope, limits remain regarding what is included under the rubric of health care. These limits are set by the moral community in how it values health care, and how it establishes norms and values around care itself. They are also indicated by the medical community and standards of medical care. And importantly, my aim is not to establish universal and wide-ranging equal access to an expanded package of care for all persons in all settings (as ideal as this might be). Instead, my focus is to expand the relevant kinds of claims one can make on others, as part of her right to health care.

What makes the vision of health care I am offering an enactment of justice is threefold. One: its aims are to relieve or minimize suffering. Some amount suffering is likely inevitable for all of us, at least at the end of life if not before. However, suffering is also heightened for certain individuals and in certain circumstances. This approach recognizes that the features leading some to suffer, or suffer more, are not only matters of moral luck, nor are they only matters of equity or equality. Heightened or unaddressed suffering is also produced through historical injustices and social oppression.

The second enactment of justice occurs by observing that there are distinct forms of suffering that are exacerbated when we lack access to care, and when we cast care as separate from questions of justice. We can attune to features of luck and history, genetic disposition and individual as well as social choices, through practices of health care. The third enactment of justice unfolds through the observation of how health care is designed and endorsed by the moral community. It is up to a moral community to determine how it spends money on research and development, health or medical education, and public programs; what kinds of practices it allows or prohibits through custom or policy; and the community members recognized as apt recipients or providers of health care. Given the ways in which the values and practices of health care are shaped by the moral community, health care is a normative practice in which the norms can and need to be continually questioned, revised, and refined.

In subsequent chapters I argue for how health care should be normatively promoted as a right within particular kinds of moral communities in ways that health - whether narrowly or expansively construed - cannot. As Daniels urges, we need theories of justice before individual rights. In the next chapter I consider how rights work, and how and if human rights work. In the following chapter I consider two ways into a traditional account of health care through rights frameworks: one appealing to the notion of human rights, the other to the notion of bodily self-ownership. I argue that they each face a conceptual problem that aligns rights with goods and focuses on rights to goods. In the fifth and sixth chapters I propose a new way forward that builds on the expanded account of health care I offer here, and the of moral community that can enact this kind of just care. I call this kind of moral community an ethical home, for reasons quite distinct from the care ethics approaches I survey in this chapter.

Conceptualizing Care

Before I analyze the compound concept of health care, and defend a particular kind of health care, I need to spend some time on the concept of care. Although I take "health care" to be more than merely the joining of its component, I understand "care" to be an important contributor to the phrase, specifically doing work around the formation of, and accountability to, a moral community. The term also to contains historical baggage in the recent history of philosophy. I follow Virginia Held in understanding care as a relational activity, that is both a practice and a value.[4] The account of care I propose arises out of feminist methodology, and, I contend, can respond to internal and external critiques of an ethics of care. First, I consider several key proposals (and several of their critiques) for conceptualizing the care that contributes to an ethics of care, and then turn to the relationship between care and justice before returning to a framework for health care.

Nel Nodding's *Caring* argued for a shift in ethical thinking away from principles and toward the affective experience of, and relations involved in, caring. She focused particularly on the moral

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[4] Held, 36-43.

exchange between the one-caring and the cared-for.[5] Carol Gilligan argued in *In A Different Voice* that the kinds of moral development and virtues that are aligned with women, and have been historically excluded from philosophical thought, are not inferior to men and typically male virtues. Instead they are merely a different voice, and one that has been largely excluded from the conversation.

Gilligan suggested that individualistic virtues of justice and the language of rights that dominate philosophy exclude relational virtues and the language of care. And while these may not be strictly or innately gendered concepts, she suggests that men tend to speak and think in terms of justice and rights, which we see reflected in traditional ethical programs, while women speak and think in terms of relationships and care.[6] Care ethics takes up the ethical framework from Noddings, the observations of Gilligan, and contributions by many other feminist scholars, to expand on what an ethic reflecting care might be.

Much feminist scholarship recalled that the family and caregiver-child relationships can provide occasion to theorize in new ways, and afford different models for thinking about concepts such as justice or care, and their relationship to each other.[7] Virginia Held, in the *Ethics of Care,* argues that care is prior to justice for reasons specific to child rearing: "without care no child would survive and there would be no persons to respect."[8] Justice cannot occur without people having and raising children to participate in society and enact justice. Although Held engages a maternal model of care built around a mother-child relationship, she acknowledges father-child relationships, as well as the potential for all parent-child relationships to be harmful or oppressive.[9]

Parental relationships can be oppressive for the parent or child inside them, or oppressive to the parent forced into parenthood. The expectations for what kind of parental role they are expected

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[5] Noddings, Nel. *Caring: A Feminine Approach to Ethics and Moral Education*. Berkeley: University of California Press, 1984. The revised edition changes the title slightly, but notably: Noddings, Nel. *Caring: A Relational Approach to Ethics and Moral Education*. Berkeley: University of California Press, 2013.

[6] Gilligan, Carol. *In A Different Voice*. Cambridge, MA: Harvard University Press, 1993.

[7] I say "recalled" rather than introduced because it is not novel in the history of philosophy to use the family or caregiver-child relationships for philosophical reflection. In ancient philosophy, for example, *City of God, The Republic,* and the *Crito* all feature arguments based on families or parent-child obligations. However, what is novel about the feminist approach is who is doing the philosophizing, the weight given to relationships in general, the specific kinds of relationships analyzed (i.e. mother child in particular), and the attention to previous exclusions of these kinds of relationships from traditional accounts.

[8] Held., 17.

[9] Held suggests that she and others appealing to maternal relationships have been too narrowly read. In her view, care does not mean a nuclear family or even merely the model of a nuclear family but includes public forms of care such as health care workers (Held, 37). However, these other kinds of care draw on a family or maternal model, nonetheless, as a conceptual springboard, one which I suggest is normative and not descriptive, including potentially oppressive norms that ought to be up for revision.

to enact may also be oppressive, especially if becoming a parent, or the social expectations of parenthood, were unchosen. Held takes care ethics to not only be an ethics of the family structure, but also to provide a "radical ethic calling for a profound restructuring of society," once the social and political implications of the view are fully understood.[10]

Noddings suggests that "human love, human caring, will be quite enough on which to found an ethic," although the caring a mother does for her child tends to be seen as natural not ethical.[11] Noddings seems to suggest that maternal caring is both natural and ethical, although there is a distinction between the natural care one desires to perform, such as caring for an infant, and ethical care.[12] The latter requires "an effort that is not needed in natural caring,"[13] though all caring requires not only the impulse to care, but also committing oneself to caring.[14]

It is the acting upon the choice to care, even if it is a naturally-inclined choice, that adds a moral valence to care per Noddings. The act of caring may be to act on behalf of a cared-for entity, or not, in cases in which a reflection of how to care in the best interest of another suggests it is to refrain from acting.[15] In this way, not all acts of care are overt actions. Attention and reflection toward care can also be ethical acts of care. While I will critique certain foundational assumptions about the historical development of an ethics of care, I will return to the concept of attention to build a different account of care.

Across the care ethics literature, the focus of care is characterized differently. Noddings takes a broad view of what care is, but sources it within families and also homes, primarily those that include families with children. I will return to the idea of home when I propose a moral community grounded in an "ethical home" in later chapters.[16] Care is a form of work for Joan Tronto and also Sarah Ruddick, whether or not it is formally recognized as such through compensation mechanisms. While Tronto and Ruddick understand care as a relationship, in addition to being and taking work, Ruddick places greater emphasis on the relational aspects of care than Tronto.[17] Noddings and Gilligan focus on affective elements of caring relationships, whereas Diemut Bubeck focuses on the

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[10] Held, 19.
[11] Noddings, Nel. "Caring," in *Justice and Care: Essential Readings in Feminist Ethics* edited by Virginia Held. New York: Routledge, 1995, 7-30, 9.
[12] Ibid., 12.
[13] Ibid., 10.
[14] Ibid., 11.
[15] Ibid.11.
[16] The vision of home to which I subscribe will not be indexed to families of direct kindship.
[17] Ruddick, Sara. "Care as Labor and Relationship," in *Norms and Values: Essays on the Work of Virginia Held,* edited by Mark S. Halfon and Joram C. Haber. Lanham, MD: Rowman & Littlefield, 1998.

functional role of these relationships to meet needs.[18] Peta Bowden takes care to be an institution that does not require a fixed definition, but rather care is simply the practice of valuing others.[19]

Joan Tronto and Bernice Fisher have developed one of the more expansive definitions of care, describing it as an "activity that includes everything that we do to maintain, continue, and repair 'our world' so that we can live in it as well as possible." This activity is not only related to the family or interpersonal care, but includes "a variety of social, economic, and political institutions."[20] Tronto and Fisher include social and institutional care, with which I agree. This is not a feature of all programs of care ethics, and is actively avoided in some (such as that of Noddings, I return to this when I turn to justice and care). Yet their definition of care is so broad that it might fail to pick out what care is, because it doesn't look like there is much that care isn't on this account.

Care ethicists enumerate different instantiations of care, as well. Held notes that "caring for" is distinct from "caring about."[21] Tronto and Fisher identify four phases of caring that include: caring about (perceiving needs); taking care of (taking responsibility); caregiving (the work of care); and care receiving (responding to the receipt of care).[22] Differences between how the term care is used, such as to care for or to care about, as well as diverse models for and foci of an ethics of care, show the necessity to clearly define care, its meaning, and scope, for it to motivate an ethics. Care ethics is a plural field, and leaves much room for distinctions and debate.

Held endorses a normative rather than descriptive view of caring relationships, including familial relationships. Although certain caring relationships create the occasions for theorizing about care, those relationships are not fixed. In her view care ethics is not a descriptive practice, but a prescriptive one: "care as relevant to an ethics of care incorporates the values we decide as feminists to find acceptable in it," and is "not reducible to the behavior that has evolved and that can be adequately captured in empirical descriptions."[23] Yet others, including Noddings, take a naturalized approach to care: a mother's care for her infant is empirically observable, and is also a fertile cite for conceptual production, in accordance with observations about the way things are. Sarah Hoagland has noted that Nodding's view has unintended consequences of reinforcing oppressive relationships

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[18] Bubeck, Diemut. *Care, Gender, and Justice.* Oxford: Oxford University Press, 1995.

[19] Bowden, Peta. *Caring: Gender Sensitive Ethics.* London: Routledge, 1997.

[20] As quoted in Brandsen, Cheryl. "A Public Ethic of Care: Implications for Long-Term Care," in *Socializing Care: Feminist Ethics and Public Issues* edited by Maurice Hamington and Dorothy C. Miller. Oxford: Rowman & Littlefield Publishers (2006): 205-226, 206.

[21] Held, 29.

[22] Brandsen, 206-207.

[23] Held, 39.

in which women are tasked with non-reciprocal obligations to care. Characterizing caring obligations as part of feminine nature or natural maternal roles conceals the structural oppression that uniquely tasks women with burdens of care.[24]

Hoagland also raises a problem with the necessary interrelatedness of caring relationships. We are already embedded in them, and once they are in place, they are not chosen, but merely roles into which we then must act. Motherhood is not a daily act of choosing to mother: once we become mothers, we are obligated to our infant whose life depends on our care. This is no longer a choice. Perhaps it never was one.[25] In the instances when one does not to care for her infant this choice-to-not-care is cast either as pathological illness, or criminal act of neglect, or both. In a sense, it looks like there is an ethical failing to not maintaining care once one is thrown into it. Yet there are instances when it is appropriate to withdraw from caring, Hoagland argues, and this is not always an ethical shortcoming.

Particularly in instances where care occurs within an abusive relationship, or enables other harms, withdrawing from care enhances "the ethical self."[26] Hoagland reflects on Nodding's examples of a mother whose "ideal" is "diminished" when her husband rapes their daughter, but also "diminished by withdrawing from him;" Noddings also considers the case of an aunt who exhibits anti-black racism, but is "otherwise a warm and generous person."[27] Hoagland says that rather than casting these behaviors as poor choices by otherwise decent people, we ought to understand these as choices characteristic of who someone is, and be able to withdraw from those who are oppressive and abusive, even if the oppression and abuse is not directed toward the self. Such a withdrawal as Hoagland describes is not merely the retraction of care, but I think also reflects a retraction from the moral community. She seems to propose a move similar to what P. F. Strawson described as taking an objective stance toward those who we wish to remove from our moral community.

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[24] See Hoagland, Sarah Lucia. "Some Concerns About Nel Noddings' 'Caring.'" *Hypatia* 5.1 (1990): 109-114.

[25] It should not be taken for granted that one has access to abortion or adoption options, for example, whether for practical, economic, or social and cultural reasons. It may not be within the person's values and world view to consider these options. Or they may not be on offer due to the operative values or policies of the community in which the person lives.

[26] Hoagland, 111.

[27] Ibid.

According to Strawson, we respond to others through reactive attitudes such as "gratitude, resentment, forgiveness, love, and hurt feelings."[28] As participants in interpersonal relationships "we attach to the attitudes and intensions toward us of other human beings… beliefs about these attitudes and intensions"[29] that make them moral emotions. The reactive attitudes express moral judgements and evaluations through practices of blame or praise. Blame and praise in this way convey value: both the value we understand others to show toward us (in treating us in a particular way) and the value they have as member of the moral community with moral standing. Yet, there are circumstances which erode at the reactive attitudes and we instead take an "objective attitude" toward a person.

This occurs when we view someone as outside the moral community or as other than a "morally responsible agent."[30] We might further distinguish between cases in which we excuse or exempt someone for their transgression leading to a reactive attitude. In the former instance, such as if we resent a person who breaks a family heirloom only to discover it was a small child who is not a fully morally responsible agent, we excuse their behavior and can release our resentment toward them (I might still be disappointed, but perhaps I have to shift my reaction to blaming myself for leaving the object within the child's reach rather than hold her blameworthy).

In the case of exemption, however, we are doing something stronger. We recognize our reactive attitude is inapt because the person toward whom we are reacting is, through her actions, revealing herself to be outside the moral community. In this instance, we take an objective rather than reactive attitude, signaling that we do not recognize the wrongdoer as member of the moral community.

Such exclusion from the moral community is reflected by what Hoagland assesses as an appropriate withdrawal from care. Hoagland is right to acknowledge the ways in which we may want to remove someone from the moral community. Furthermore, Hoagland's critique of Noddings illustrates one way in which practices of care are practices within, and constitutive of, a moral community, in which care expresses normative practices and values shaped and held by the moral community. Withdrawal from care is, in a sense, to take an objective stance and communicate that someone stands outside a moral community and its values.

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[28] Strawson, P.F. "Freedom and Resentment." *Freedom and Resentment and Other Essays.* New York: Routledge, 2008, 5.

[29] Ibid.

[30] Ibid., 15, 18.

I want to clearly distinguish between withdrawing from care and the withdrawing of care. My focus here is withdrawing from caring relationships and practices across all kinds of relationships in which the work of care occurs. This is distinct from the idea of withdrawing of care in a medical setting, which we should more accurately term withdrawing treatment: care continues, even if ongoing treatment is no longer appropriate for a patient. In cases of withdrawing treatment, the application of care becomes all the more important for a patient's comfort. We could further imagine circumstances when we are inclined to withdraw from care and caring relationships for someone whose medical treatment needs to be withdrawn as an emotionally protective mechanism, but that in such cases a withdrawal of practical care is not appropriate. In these situations, a division between affective care relationships from family and friends, and professional caring relationships from health care workers, for example, might be applicable.[31]

Hoagland's point about withdrawing from care also raises questions about the boundaries of the chosen and unchosen in relationships, and in care, which are worth further consideration. To some extent these boundaries are both chosen and given. In many instances we are always already thrown into caring relationships, yet it can be possible, and appropriate, to withdraw from them, as Hoagland says. It can also be the case that we have obligations to continue caring, despite a preference to withdraw from these obligations or care relationships.

Care is not always, or is often not, best characterized as choice. Annemarie Mol distinguishes between a logic of care and a logic of choice. While Hoagland's critique of Noddings is fruitful for refining an operative definition and practice of care, it also operates according to a logic of choice. According to Mol, a logic of choice prioritizes autonomous moral agents who are free to (and expected to) make individual, isolated choice. This logic fails to recognize the ways in which choices are often already limited for us within our contextual constraints, and also how individuals are participants in a web of interaction instead of being isolated agents. Furthermore, the logic of choice is also a logic of guilt, and places blame on individuals for their putatively chosen circumstances. For example, if I am unable to care for my kids, this is my fault for choosing to have children.[32]

Part of my critique of health in the previous chapter was related to how accounts of health hold individuals uniquely, and at times unjustly, blameworthy for their health. This is in part because health often (in the United States setting) also subscribes to a logic of choice. Mol's analysis of a

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[31] Though on the whole I think care ethics gives us good reason to problematize distinctions between professional and intimate or private and public forms of care.

[32] Mol, Annemarie. *The Logic of Care: Health and The Problem of Patient Choice*. New York: Routledge, 2008, 91.

logic of choice helpfully brings to light the frequent mischaracterizations of many of the things we presume to be choices, that are instead the products of long histories of structural oppression or injustice. The person who "chose" to have a child might not have access to birth control or education around contraception. The person who "chose" to have a child might have been raised in an environment that did not allow for women to make choices about their own bodies, such as when and with whom to have sex, or the choice to use contraception or access abortion services.

In contrast, according to Mol's logic of care (and we might say the insight of care ethics broadly construed) we are not independent individuals making our isolated choices who then form into social collectives in which we get or receive care. We are always already formed within a collective. Identifying the bounds of a collective is not done by adding individuals together, but by "making helpful differentiations between groups,"[33] such that collectives are always the starting point, and the result. In this way, Mol retains the emphasis on interdependence from care ethics, suggesting that care ethics is "something people shape, invent, and adapt, time and again, in everyday practice,"[34] but largely sidesteps the gendered history of care by emphasizing the role of collectives, though not necessarily the primacy of the family as a paragon collective and the gendered social roles that the family inherits and reproduces.

Additionally, Mol's view paints care as a process, without clear boundaries. It is open-ended, unlike choices for or between fixed, bounded, options.[35] She describes the main moral action in a logic of care not as one of making choices, but instead as "engaging in practical activities" in which "what it is to do good… is not given before the act."[36] Values are formed through the process of caring, such that "defining 'good,' 'worse,' and 'better' does not precede practice, but becomes part of it."[37] Like Hoagland's observation that withdrawing from care can be an ethical act, which I am suggesting is the work of moral community formation and management that care enacts, care also enacts and shapes the values of the moral community through the very practice of care.

We can reflect on how we shape the norms of caring relationships, even if we cannot entirely choose for or against caring relationships. The caring relationships modeling an ethic of care, including motherhood or parenthood, are normative. I think Held is correct to suggest that the contents of "care" are open to what we determine is appropriate to them rather than being fixed by

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[33] Ibid., 68.
[34] Ibid., 5.
[35] Ibid., 20.
[36] Ibid., 86.
[37] Ibid., 87.

empirically observable fact. To suggest the mother-child relationship, for example, reveals some deep nature about the way things really are in an analytic a priori sense is to misunderstand something about the critique of knowledge and of the history of philosophy that feminist and critical race or disability scholarship brings to the field.

The role of "mother" is a norm that, at least from where I sit, is currently up for dramatic revision as feminism recasts the expectations specific to women and mothers as (often unjust) social constructs. A mix of queer theory, reproductive technology, and new kinds of gender, marriage, and family social constructs are recasting who becomes parents and how. Radical feminist and queer critiques have challenged the social constructs in which we parent, arguing for example, for communal child-rearing.[38] While contract surrogacy, though a contentious practice, upends assumptions about who are natural or biological parents, and what bonds, rights, or obligations they have as such.[39]

Critiques like Hoagland's worry about the unchosen and oppressive relationships between mother and child, although the mother child relationship is also a starting point for much theorizing about care. Yet another view of care ethics accepts inequities between caring and cared-for agents. This does not mean that such views need to accept oppression and injustice – they don't – but they do not start from a place of presumed equal standing across all moral agents. A parent/child model is only one instance of inequality between agents (though some would say that the infant or child is not even an agent, though she does have some moral standing, and certainly has interests).

For Noddings, she imagines the caring one must act on behalf of the cared-for, including choosing, when it is appropriate, not to act if that is in the best interest of the cared-for. The caring-one is determining care in a situation where the cared-for cannot speak for herself, such as the case of a young infant.[40] This is not the only model of caring relationships in all settings, nor the only model of vulnerable agents. While it is appropriate to critique care ethics that would excuse structural inequity and oppression as merely reflecting the essential nature of certain relationships, it is also an important feature of care ethics that it works from the premises that relationships are unequal, that needs are diverse, and that we start from different positions of vulnerability and

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[38] For example, see Card, Claudia. "Against Marriage and Motherhood." *Hypatia* 11.3 (1996): 1-23.

[39] For a small selection of early entries into the commercial surrogacy debate see: Anderson, Elizabeth. "Is Women's Labor a Commodity?" *Philosophy & Public Affairs* (1990): 71-92 and Anderson, Elizabeth. *Value in Ethics and Economics*. Cambridge: Harvard University Press, 1995; Wertheimer, Alan. "Exploitation and Commercial Surrogacy." *Denver University Law Review.* 74 (1996): 1215-1229; Epstein, Richard A. "Surrogacy: The Case for Full Contractual Enforcement." *Virginia Law Review* (1995): 2305-2341.

[40] Noddings, "Caring," 11.

resources. The usefulness of this observation is not to be prescriptive about the nature of particular relationships or roles to say they necessarily must be so, but instead to navigate, adjust for, and appropriately respond to the structural or power differences that are realistically present in them.

As Mol observes: "In the logic of care we are not equal. But the difference between us has little to do with hierarchy… what matters are the horizontal differences between people. These index different needs, and more particularly different needs for care."[41] In this way the logic of care allows for the categories of classification or differentiation to be plastic, and to evolve as norms and practices evolve. This is particularly useful because it allows for an ethic of care to effectively work in non-ideal settings. It does not require imagined, ideal, reasonable, and rational citizens. That is not the world we live in. It likely won't be the world we live in. We still need an ethics we can live in.

Although Noddings appeals to a naturalized care, what we should retain from her account is the source of moral obligation to the other is the "value I place on the relatedness of caring."[42] According to Noddings there are two criteria governing obligations that are "limited and delimited by relation." These include an "absolute" condition that there is a present relationship, or, importantly, the potential for one; and a "priority" condition informing how we prioritize our care according to the "dynamic potential" for growth of the relationship "including the potential for increased reciprocity and, perhaps, mutuality."[43]

The kinds of relationships in which care occurs would ideally have the potential for reciprocity and mutuality, but reciprocity and mutuality are not necessary conditions for care. I take this to mean that a kind of co-engagement occurs in relationships in which two or more agents are involved, but that co-engagement does not hinge on reciprocity. Reciprocity suggest a parity of exchange. Noddings distinguishes reciprocity from mutuality in a way that suggests mutuality is a higher form of shared exchange than reciprocity. We might infer from her formulation that reciprocity is about the fact of the exchange, but in which unequal but still reciprocal exchange can occur. Whereas mutuality is about the quality of the exchange, as well as commitments to sharing or equality that motivate it. Yet neither reciprocity nor mutuality are required of a present relationship, they are only part of its "dynamic potential."

Co-engagement, as I see it, requires that all involved parties to a relationship express or acknowledge engagement, but not that they meet each other in any form of exchange, whether equal

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[41] Mol, 72.
[42] Noddings, "Caring," 13.
[43] Ibid., 15.

or not, mutual or not, shared or not. This might look like a situation in which an individual's expressed need for care is her engagement in a relationship in which she will not be able to reciprocate the care she requires. Yet her expression of need invites another to respond through care, and thus this generates a form of co-engagement.

Reciprocity might also suggest that the caregiver is having her own need fulfilled by caring. But this over-idealizes care. Providing care might be undesired, unchosen, and unfulfilling, yet may still be an obligation to which we are required to attend with co-engagement. I think we need to be able to accept that giving care might not always be directly or mutually beneficial to the caregiver, and that care may not always, or even often, be expected to be reciprocally returned.

Abandoning a strong requirement of reciprocity or mutuality in favor of co-engagement has its benefits and shortcomings. One clear benefit is that it does not take care to be a quid pro quo exchange. One shortcoming is that while these conditions work well on an individual to individual level, they become more difficult to adjudicate when it comes to collective action and collective responsibility. And of course, because reciprocity or mutuality are not necessary nor sufficient conditions for care does not mean they are not preferable or aspirational conditions for care.

Thinking about what care looks like within and among collectives is part of the public ethic of care conceptualized prominently by Joan Tronto, as well as Cheryl Brandsen, and others. A public ethic of care explicitly moves care out of its historically privatized sphere. Their views, along with that of Mol, lead toward a bridging of justice and care that I explore in the next section.

Care and Justice

How care should or does interact with justice is a point of debate in the literature. Held says "care fosters social bonds and cooperation" while "justice protects equality and freedom," and these represent "very different emphases in what morality should consider."[44] On her view, a sufficient moral theory needs to accommodate ethics of care and justice, but not combine them.[45] Yet Sarah Ruddick, for example, argues that justice works in tandem with care.[46] Held offers the example that "equitable caring is not necessarily better caring, it is fairer caring. And humane justice is not necessarily better justice, it is more caring justice."[47] Yet we might wonder whether fairer caring is in

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[44] Held, 15.

[45] Ibid., 16.

[46] As characterized by Held, 15.

[47] Ibid., 16.

fact always more just caring, and what it means to care fairly. We might also wonder whether inhumane justice is just. It seems treating care and justice as distinct concepts might not necessarily serve the ends of either. And further we might wonder whether this distinction is yet another false dichotomy historically constructed along with distinctions between public and private spheres, or male and female social roles.

Marilyn Friedman wondered if it is possible to integrate justice and care, which she, like Held, characterized as "two distinct forms of moral commitment."[48] She concludes that we cannot "respond to all persons equally well in either way," and "the only integration possible here may be to seek the more intimate, responsive, committed relationship with people who are known closely, or known in contexts in which differential needs are important and can be known with some reliability, and to settle for rule-based equal respect toward that vast number of others whom one cannot know in any particularity."[49] However, the objective of care, and particularly of care justice, might not be to respond equally well to all persons, but instead to recognize that some response is due to those with whom we engage in a moral community. In fact, internal to our moral communities, as I will argue in subsequent chapters, we have particular obligations to some members due specifically to their differential needs that are caused by the practices of the moral community.

The image of a mobius strip that Elizabeth Grosz applied to the concept of gender is a useful image for the interrelation of many traditionally dichotomously constructed opposites.[50] In this spirit, I do not take justice and care to be two distinct options, nor do I take public and private, or intimate and stranger relationships to be bright lines that divide care from justice. Both the public and private, intimate and anonymous, comprise care justice. Yet, often care connotes the private and intimate, in which care is primarily or initially theorized through special relationships with particular obligations such as within a parent-child dyad.

Friedman suggests the "insight that each person needs some other in her life who recognize, respect, and cherish her particularly in its richness and wholeness is the distinctive motivating vision of the 'care' perspective."[51] According to this insight, it is not common humanity that motivates respect but "a respect for individual worth, merit, need, or even, idiosyncrasy… which involves admiration and cherishing, when the distinctive qualities are valued intrinsically, and which, at the

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[48] Friedman, Marilyn. "Beyond Caring: The De-Moralization of Gender" in *An Ethics of Care: Feminist and Interdisciplinary Perspectives* edited by Mary Jean Larrabee. New York: Routledge, 1993, 270.
[49] Ibid., 271.
[50] Grosz, Elizabeth. *Volatile Bodies*. Bloomington, IN: Indiana University Press, 1994.
[51] Friedman, 270.

least, involves toleration when the distinctive qualities are not valued intrinsically."[52] Friedman's assessment is helpful to hang together an array of views in care ethics around their common features.

At the same time, its conclusion does not go far enough. Does toleration motivate care in the same way or at the same level that respect does? Our instinct is that it probably does not. Do we merely accept that individuals who are less valued for their distinctive qualities have fewer caring resources? And can institutional or non-intimate care fit with the notion of care as responsive to individual cherishing? It becomes clear on this view why justice and care cannot fit together, unless as a matter of justice individuals are due intimate, cherishing relationships. This cannot be the case. Individuals have different background resources to bring about intimate caring relationships, and various fortunes or misfortunes that lead to the creation, maintaining, or dissolution of intimate care. Some people simply have more caring resources than others.

We might want to say that this is in virtue of how that person has cultivated her intimate relationships: she has shown respect, cultivated virtues, and in turn receives respect and "cherishing." This returns us, however, to the logic of choice instead of a logic of care. Medicine is full of the kind of judgement that some folks get what they are due for "making their choices." They chose to smoke tobacco, have poor dietary practices, or not exercise, resulting in various morbidities. Or they chose to not form and maintain intimate relationships, to not have children, or to treat intimates badly such that there is no available caregiver in a time of medical need. These are cast as autonomous decisions, and assumes that all deciders are freely-choosing rational individuals who have knowingly entered into their decisions.

Again, feminist critique and accounts of relational autonomy help unpack this perspective.[53] Just as individuals are socio-historical selves,[54] so are our caring structures socio-historically produced. Deeply rooted structural injustice can impact an individual's abilities to form and maintain sound intimate relationships, including features such as: mental illness; histories of trauma and abuse; resource disparities that force people to leave loved ones to pursue a more financially, socially or politically viable situation; or mere luck, which might lead one to form various relationships and

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[52] Ibid.

[53] For example: Friedman, Marilyn. *Autonomy, Gender, Politics*. New York: Oxford University Press, 2003. Mackenzie, Catriona and Natalie Stoljar, editors. *Relational Autonomy Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press, 2000; Meyers, Diana T. *Self, Society and Personal Choice*. New York: Columbia University Press, 1989.

[54] Christman, John. *The Politics of Persons*. Cambridge: Cambridge University Press, 2009.

then through no particular fault, be left in the situation of requiring care without those people who comprised your intimate relationships, such as having partner or children pre-decease you.

As Held notes, care is a relational enterprise[55] that has often been miscast only as an activity (to care for), characterized primarily as labor, even if a "labor of love."[56] In our colloquial usage we modify "care" to talk about "caring for" as an activity (though it can also be a preference) and "caring about" as regard. In Held's view, the practice of care can capture these different kinds of care, as well as the whole scope of the caring relationship rather than focus merely on the one doing the caregiving labor while leaving out the care recipient.[57]

My worry remains, though, that even if care, like justice, is a value in addition to a practice, and this value includes "a cluster of moral considerations, such as sensitivity, trust, and mutual concern, with which to evaluate such practices,"[58] we tend to care for (in the activity sense) those who we care about and for in the sense of preferring or liking. Held says that we "value caring persons in caring relations," so that care is not only a virtue but a practice based in relationships.[59] But it looks like we might still give those with caring dispositions, and those for whom we are partial, a leg up in accessing care.

We can, and should, however, push care beyond the practice of individual cherishing. Even if some people having children is necessary to produce future generations of a moral community to enact justice, having children ought not be the requirement for receiving future care, and care should not be the motivation to have children. If this is the case, it looks like we are doing something wrong about how we shape and understand our caring duties and expectations. Care needs to be both intimate and institutional, and we need to establishes practices to institutionalize kind of care that have previously been relegated to intimate spheres. Care justice collapses distinctions between theory and practice, public and private, justice and care.

Yet a persistent problem for care's relationship to justice is its relationship to institutions. Noddings thinks that institutions "in a deep sense" cannot be "ethical." Instead, "only the

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[55] Held, 36.

[56] See Kittay, Eva Feder. *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge, 1999 and Tronto, Joan "Vicious Circles of Privatizing Care," in *Socializing Care: Feminist Ethics and Public Issues* edited by Maurice Hamington and Dorothy C. Miller. Oxford: Rowman & Littlefield, 2006, 5. Held says explicitly that care is not equivalent to an ethic of love or relational ethic. Held, 9.

[57] Held, 36-37.

[58] Ibid., 38.

[59] Ibid.

individual can be truly called to ethical behavior."[60] This kind of ethical care then does not occur at the institutional level. Yet institutions are also what reinforce justice and create accountability. Most of our interactions are not merely between you and me sharing a piece of cake and making certain each has an equal slice so no one gets less than what she is due. And, although some of us have trouble asserting our needs or confronting the other who we think has wronged us in these small yet present infractions, they are the easiest to rectify. We can announce our grievance, or we can establish practices in the moment to ward against injustice: I cut the cake and then you choose your piece, for example.

As Noddings says: "ideally, another human being should be able to request, with expectation of positive response, my help and comfort. If I am not blinded by fear, or rage, or hatred, I should reach out as one-caring to the proximate stranger who entreats my help."[61] This is what it is to care, on Noddings' view. While we might see how this account allows for vulnerabilities that do not make us obligated to offer care in all situations (that is to say, toward all strangers any time we are potentially available to respond with care), we also inherit and receive biases that impel fear, rage, or hatred through histories of inapt relationships and faulty care.

Not responding with care can be a vicious and self-fulfilling cycle of making the other more deeply and fearfully "other," withholding care, and justifying this withholding out of the fear that only reinforces the othering process. Derrida's autoimmune logic of hospitality offers a parallel to care that suggests why care withheld in fear could be a faulty version of a logic of care. For Derrida, autoimmune logic, like biological autoimmunity, is the paradox that the very thing that protects you, the immune system, is also the thing that turns on itself to destroy you or lead to illness as autoimmune disease. Hospitality follows an autoimmune logic because that which is necessary for hospitality, to take in the stranger, is also a perpetual threat that the stranger will harm you, overtake you, or kill you. Complete hospitality, according to Derrida, is to welcome unconditionally he or she who is a complete stranger. And this radical hospitality without condition always contains the risk that the stranger, once welcomed, poses a threat.[62]

We might wonder if care, like hospitality, can be complete if we withhold it from those who we receive with fear, or rage, or hatred. At the same time, extending care to those who make us feel

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[60] Noddings, "Caring," 29.
[61] Ibid., 27.
[62] Derrida, Jacques. "Hostipitality." Translated by Barry Stocker and Forbes Morlock. *Angelaki, Journal of the Theoretical Humanities* Vol 5.3 (2000): 3-18.

so intensely vulnerable might be part of the internal oppression Hoagland charges Nodding's care enacts, and why it can be most appropriate and ethical to withdraw care. We observe that a woman driving alone down an isolated road at night might not stop to offer assistance to the person whose car appears to be broken down at the side of the road out of fear around her own safety in that situation. This fear could be informed by her own history of assault or a reasonable fear of such an occurrence, and this is in part because of histories of misogyny and abuse toward women that produce and reinforce such fears.

We might also observe a police officer who responds to a large young black boy by profiling him as a criminal rather than talking to him. The officer does not engage the boy in a caring exchange by taking an interest in him, or trying to connect. Instead he encounters the stranger with fear, or even hatred, and this fear and hatred is received through a deep, institutionalize, history of anti-black racism. By consistently not extending care, the withholding of care reinforces fear and hatred that leads some white police officers to respond to unarmed young black boys by shooting them rather than engaging them, because the white officers perceive them as a threat rather than attend to them with care.

One route out of this problem of individual vulnerability, or bias, fear, or hatred, entering into and limiting the administration of care is to bolster institutional responses of care rather than rely on individuals to exclusively extend and fulfill obligations to care. This is not to suggest that institutions do not also reproduce fear, hatred, or rage in systemic and structural ways. They do. Institutions might be, in many cases, the source of individual fear, hatred, or rage toward unknown others to whom we react in these ways due to structural injustices. But making care at least partly institutionally accountable can respond to, and begin to address, both the historical biases that lead to fear or hatred (according to race, gender or ability markers, for example) that are institutionally reinforced, while administering care that is not reliant only on individuals who respond with fear or hatred out of their perceived vulnerability in a situation. Connecting care to institutional response and accountability is a reason to connect it to, not separate it from, justice. Yet this connection between care and justice, or care and institutions, is tenuous in the standard care ethics literature.

Noddings claims that "only the individual can be truly called to ethical behavior" and "the way to enhance the ethical ideal, the commitment to caring, invokes a duty to promote skepticism" regarding institutions, because, "in a deep sense, no institution or nation can be ethical."[63] This

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[63] Noddings, "Caring," 29.

assessment of institutions is both right and wrong: we do need to appeal to units other than the nation state, which, for reasons I discuss in the next chapters, are limited by the mechanisms of citizenship to act justly toward those inside its boundaries.

But this does not negate that we should and could aim for institutions that are both ethical and accountable. While I do not agree with Noddings that the individual is the only one truly called to ethical action, we can push for why and how the individual is accountable as part of collective action and responsibility, which I turn to in the fifth and sixth chapters. Furthermore, drawing a bright line between the individual and the institution as a dichotomy in which only one side can be ethical or caring creates an unnecessarily rigid distinction where there need not be one.

Building upon the internal critiques by feminist scholars of care ethics, we need to transcend dichotomous thinking that reproduces a binary between care and justice, just as we want to transcend other rigid and marginalizing dichotomies such as between public and private, or male and female. A tension in the feminist scholarship, for example, is the dual appeal to turn toward traditionally private sphere domains like the family and child rearing for ethical theorizing, and to break down a strict boundary between public and private spheres. A worry I have in appealing to the "care" in health care is that this will be misunderstood as a private or exclusively intimate interpersonal endeavor, which is not my intent. Aligning, rather than distinguishing, care and justice, further draws care into the public, social, and political realms.

Tronto and Held, for example, explicitly engage a civil society in care. Tronto observes that: "the language and framework of market choices guide how we describe and think about care options. The effect of this framework is to make care primarily outside of public concern. One way to understand care inequalities is to see them as the outcomes of 'choices' that competing actors make in the marketplace."[64] This is the kind of care that occurs within what Mol describes as the logic of choice, and not a logic of care. But Tronto is correct to illustrate that care is often only framed within this logic of choice, and certainly health care in the United States, as I discuss later in this chapter and the chapters that follow, subscribes on many levels to market thinking and individualized logics of choice. This poses a problem for care, including health care.

Upon deeper reflection, it starts to look like supposed choices are not really choices after all. Systemic or structural reasons contribute to, or even motivate, the situations in which people find themselves. Yet these structural and system features are often concealed, while individuals tend to be

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[64] Tronto, "Vicious Circles," 9.

held uniquely responsible for their circumstances: individuals are both blameworthy for creating their circumstances, and the only one who could have brought about change for themselves.

At the same time, is it not a choice to care? And a choice not to care? Part of what I am exploring in these pages is that care is complicated by factors that are both chosen and unchosen, and is more complicated than being merely a choice between two options: choosing to care or not to care. It is also about commitment, response, and demand. Certainly, there is a choice to offer care or not (and in more limited ways, to accept or refuse care, though this may not be possible for those most vulnerable, and this is instructive as to how care does not hinge on its chosenness).

As already noted, this is a tension within the literature: care is both always already a structure into which we are thrown, yet to appeal to naturalized care is to reinforce oppressive normative systems; apt care is to persist in caring despite desires to withdraw, yet withdrawing care is perhaps the most ethically appropriate response to those who fail to be members in good standing within a moral community. Mol's logic of care does not remove the possibility for care to be an active choice. But it does shift the perspective so that choosing is not the primary moral act, caring is. And because caring is not merely a choice between things, it opens up a more open-ended and generative space for creative solutions.[65]

Therefore, a caring logic deconstructs otherwise untenable binaries such as between the chosen and unchosen, or care and justice, private and public, or natural and normative, defying the requirement to choose between two options by opening up a creative space to generate something new. Care interrupts a logic of choice, though as Tronto notes, "part of the social logic of care… is **not** to think about care."[66] Choice obscures and constrains care.

Derrida describes deliberative choice as disjunction, which presents an "interruption" or "unbinding."[67] The disjunction indicates options between elements, though it also holds them together. It opens a deliberative process. One must unbind the disjunction and pick a side, or include them both and rebind them. This is an active deliberation introduced by the disjunctive interruption. When considering democracy Derrida says that at the moment that "action follows knowledge as calculable consequence," when one "**knows** what path to take, one no longer hesitates."[68] A disjunction presenting a choice is an invitation to enact democracy by choosing

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[65] Mol, 100.

[66] Tronto, "Vicious Circles," 15. Emphasis in original.

[67] See Derrida, Jacques. *Rogues.* Translated by Pascale-Anne Brault and Michael Nass. Stanford: Stanford University Press, 2005.

[68] Ibid., 84. Emphasis in original.

according to justice and responsibility. But once a choice is made, then the interruption is over, and democracy is no longer open, but foreclosed.

Derrida thinks that democracies with only two major parties are not especially democratic. They have only a single disjunction, a choice between two: "nothing is less democratic than limiting the number of parties to two."[69] This observation reflects a danger of a logic of choice, especially when the choices have already been narrowed by externally imposed options. Choices are not as freely chosen as they initially appear, and we are already constrained by the need to choose between them. This is a limiting constraint for justice, especially when no available option is fully just. Care, on the other hand, can remain open as a creative, collaborative, and evolving practice, within intimate encounters of care and within broad communities and institutions.

According to Tronto, there are three presumptions of care as public: First, "everyone is entitled to receive adequate care throughout life." Second, "everyone is entitled to participate in relationships of care that give meaning to life." And third, "everyone is entitled to participate in the public process by which judgements about how society should ensure these first two premises."[70] Therefore, is not enough to think about care as a good for distribution, rather it requires public, political processes.[71] Cheryl Brandsen builds on Tronto's notion of a public ethic of care to conclude that deliberative democracy is not at odds with an ethic of care, but is required for a public ethic of care.[72]

This public ethics is a response, as Brandsen says, to a tendency to view care as localized and limited to caring for one's own.[73] Caring for one's own might not be the problem of such a view as much how you define to whom you belong, and to whom you have obligations to care. Building a care ethics on the family, and narrowly construing for whom we have responsibility according to this intimate model, is insufficient for a public ethic of care. Yet an ethic of care need not narrowly understand who are "one's own" fellow members, and for whom we ought to care.

Mol notes that a logic of choice assumes we form collectives with other similar members,[74] that is to say, those who we recognize as like us (or, to recall Noddings, those to whom we do not

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[69] Derrida, Jacques. *The Beast and the Sovereign, Volume 2.* Translated by Geoffrey Bennington. Chicago: University of Chicago Press, 2010, 233.
[70] Tronto, "Vicious Circles," 19.
[71] Ibid., 20.
[72] Brandsen, 223.
[73] Ibid., 207-208.
[74] Mol, 72.

react with fear, hatred or rage because they are different from us). Care creates the possibility to understand "our own" differently and more inclusively, as those who participate and engage in caring practices and values as recipients and providers of care. There are ways that care can expand who we understand to be "our own" to whom we owe obligations of care and from whom we can expect care, that does not track onto familial or citizenship relationships.[75]

For Brandsen: "As a moral value, a public ethic of care seeks to assure good care to all members of society."[76] According to her framework, this public ethic of care: identifies needs of caregivers and receivers; is wary of how needs get filtered and who determines them; has mechanisms in place for caregivers and receivers to express needs; develops policies that affirm a "social conception of the self;" and "requires "collective responsibility for protecting the welfare of vulnerable groups, including those who do the work of care."[77] The best way to achieve this public ethic of care, on her view, is through process of deliberative democracy.

While this is one way into a public ethic, I am not convinced it is also a way into an ethic of care. Connecting the objectives of an ethic of care to deliberative democracy risks overly idealizing the mechanisms of deliberative democracy. It also might not go far enough to truly take responsibility for others, especially those others who in practice are too often left out of the deliberations. On the one hand, Brandsen notes the need to particularly protect the most vulnerable, who are often also the ones doing care work. Ideally, deliberative democracy would ensure equal participation even to the most vulnerable, and the possibility for their concerns to be voiced and acted upon in a deliberative framework.

On the other hand, deliberative democracy mechanisms tend to flatten out difference by promoting equal participation and impartiality. Equality and impartiality can be positive values, which aim to equally distribute power and decision-making. Yet in plural and diverse settings they can also obscure cases of marginalization or oppression.[78] Vulnerable minorities may not have the standing to propose necessary special protections or the steps required for rectifying marginalization or exclusion. And oppressive majorities will always outnumber minority votes, reinscribing majority

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[75] I return in much more detail to my own program for how we create an inclusive yet delineated moral community in chapters five and six.

[76] Brandsen, 208.

[77] Ibid., 209-210.

[78] This view is a version of Young's critique of Rawls in *Justice and the Politics of Difference.*

interests, which are mistakenly touted as impartial, when in fact they are merely the most prominent interests.[79]

Furthermore, while Brandsen notes that those in caring roles tend to be among the most vulnerable, her schema does not restructure care to rectify this unjust vulnerability. With the practice of care, I think we can move beyond the family or the state as our options for caring community. We do not only have two choices to either engage in deliberative democracy or to engage in intimate relationships.

Held acknowledges that "justice in all its forms requires impartiality, treating people as equals, and recognizing their rights" and that values of care need to be clarified in order to "advocate for their relevance for many practices form which they have been largely excluded," such as a practices associated with justice.[80] On Held's view, justice and impartiality are separate from care, which allows for, or even requires, partiality. Justice and care they may be able to be brought together in more instances than we generally recognize, however one is always prior to the other, and which one takes the lead in directing action or policy is context-dependent. Held suggests that there are instances in which care should lead, and justice should be a secondary consideration, just as there are instances in which justice should lead, though care should "not be absent," such as when establishing legislation.[81] Yet she also suggests that while there may be "potential conflict between care and justice, friendship and impartiality, loyalty and universality" at the same time "there need be no conflict if universal judgements come to incorporate appropriately the norms of care previously disregarded."[82] Although justice and care are distinct modes of practice and engagement with others, they need not be adversarial.

There is much to endorse of Held's view, and I adopt the general shape of her definition of care as relational practice and value, that also has institutional, public warrant beyond mere individual interpersonal relationships. Yet I also wish to push beyond her view of care and justice as complementary yet distinct features of a moral community. Instead, I invite the idea that care

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[79] We might note that what the majority holds to be their interests may not in fact be their interests, however. We see this with many white working-class Americans who endorse conservative politicians because their views align with white supremacists or patriarchal values to which the majority adheres, even if other conservative policies such as economic policies are not in their actual interest. The difficulty of disaggregating these various group identities, differences, and interests leads to perhaps incorrect conclusions by the electorate of what is in fact in their best interest or what values they hold across different spheres.

[80] Held, 39.

[81] Ibid., 41.

[82] Ibid., 11.

practices enact justice, and justice requires attention to care practices. Held makes an opening for this view by suggesting that universal judgements ought to make space for new norms that recognize the role of care. How such a care justice unfolds occurs through the practice of care, which I begin to address here, and expand up on in my account of moral communities in subsequent chapters.

Health care justice motivated by concepts of health (instead of health care) fails in specific ways. Similarly, health care justice not motivated by care is not just. A view of "health care" can bring a richness to the concepts of care and to justice. My stance throughout this work is that moral theory arises through the practices themselves. What this means for health care, then, is we cannot have a theory of health care outside of our practices of health care because the theory and practices arise in conversation with each other.

The practices of health care reflect the values internal to the theory, yet the theory responds to the evolving capacities within the practices, and both are socially-shaped constructs. Moreover, the practices of health care are instructive regarding practices of care, and reveal something about rights and practices of justice. I will say more about rights in the next chapter. But health care practice can contribute to a broader conceptualization of care. Next, I turn to an account of how principles of narrative medicine and narrative practice in medicine reveal a process that can inform and guide a theory of care.

The principles of narrative practice in medicine, as proposed by Rita Charon, are those of attention, representation, and affiliation.[83] "Attention" means that the medical practitioner directs her attention to her patient's story, to attune to and receive it. "Representation" is not merely the witnessing of a patient's story at work, but is the active engagement with the story, in which the practitioner represents it for herself and also back to the patient, co-constructing the story between the teller and the listener. "Representation" occurs through the active listening of "attention" rather than a passive listening.

Attention and representation, when fully realized, achieve "affiliation" between the practitioner and her patient. This affiliation is a form of cohesion that builds trust, collaboration and contribution toward a shared goal. In the setting of a clinical encounter between a physician and patient, this goal might be to support a shared view of the patient's health (and here I think it is

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[83] Charon Rita. "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust." *JAMA*. 286.15 (2001):1897–1902; Charon, Rita. *Narrative Medicine. Honoring the Stories of Illness*. New York: Oxford University Press, 2008.

important that this be a pluralist view of health in which the patient and practitioner construct that ideal together).

Notably, the caring relation between patient and practitioner does not exist prior to its formation through the clinical encounter (it is not a longstanding or intimate relation from which a caring practice emerges, but is created as a caring practice through the caring relationship). It is also co-dependent on both participants to form and contribute to the relationship, its practices, and a shared goal. Though it does not require or expect equality between participants. And it does not presuppose any particular kind of cherishing or caring for in the sense of liking or preferring.

This model of narrative practice affords an apt model for care practice, in which caring exchange forms and coheres moral communities, which are held together through affiliation. Care produces affiliation through interpersonal encounter, trust, attention, representation, collaboration, and contribution toward a shared goal. I say a great deal more about my concept of moral community, including the nature of shared goals to motivate moral communities, and the rights and responsibilities that arise from this particular vision of moral community, in subsequent chapters. For now, the key building blocks of my argument in this chapter are that enacting care is a constitutive practice of moral community, and the value of care arises out of its practice as a necessarily relational activity.

This definition features into my account of "health care" to which I turn next. This account of health care extends and develops the ways in which care is collaborative, expressive, and a hybrid public and private concept. It also anticipates the need to revise a concept of moral community that can meet these care justice demands.

An Expanded View of Health Care

In the previous chapter I described health care as a normative concept. I also claimed that the relational nature of health care is what makes it special. In this chapter I have emphasized that care is a relational practice that arises within and shapes the social structures and realities of caring relationships between individuals, and between individuals and institutions. It is the relational nature of health care that also produces rights to and responsibilities for health care, by enacting a kind of care justice that, through practices of care, is responsive to the demands of social justice. Before providing a more detailed account of what kind of health care achieves such care justice, I will briefly touch some key limitations to standard accounts of health care, and one proposal of health care that places an emphasis on care. The latter view focuses on care, but for the wrong reasons, because it is committed to a faulty conception of health.

From the previous chapter we can recall that Daniels understands health care to be special because of its relationship to health. Health, "is of special moral importance to us because it contributes to the range of opportunities open to us," so it is also of moral importance to address "the socially controllable factors that promote health – medical services, traditional public health, and the distribution of the broader social determinants of health."[84] These socially controllable features are all in the service of health needs, but not care needs. Daniels does not even use the term "health care" to address socially controllable factors related to health. Elsewhere he suggests that "the term 'health care' is used broadly to include personal medical services, preventative medical and public health measures, including health and safety regulation, and certain social support services for the chronically ill or disabled."[85]

This vision of health care is largely equivalent to medical care. The only reason for other kinds of supports to enter the scene is when individuals are living with chronic illness or disability. Daniels limits social services as due to those who, in his vocabulary, cannot be restored to species typical function by medical services. An example is providing seeing eye dogs for blind persons. Daniels recognizes that "medical services and social support services that meet health-care needs have **the same rational and are equally important** (his emphasis)" though indicates that "for various reasons" related to the profitability and prestige of medicine, "our society has taken only slow and halting steps to meet the health-care needs of those with permanent disabilities. These are matters of justice, not charity."[86]

Daniels is entirely right to emphasize that social supports are a necessary part of health care and health care justice, not charity. Yet what he gets wrong is his narrow view of to whom such non-medical health care is due. This places undue emphasis on a normative notion of normal functioning against which I argued in the previous chapter. And it fails to recognize the many ways that persons are excluded from social and medical goods necessary to support their overall health care. While my view is not incompatible with Daniels's view of supporting medical services, safety regulations, and public health measures as well as contributions to social determinants of health, by

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[84] Daniels, 2008, 21.
[85] Daniels, 1985, ix.
[86] Ibid., 85.

shifting the focus away from health and onto care I take up a different focus, with results that I think are more urgently, but also immediately, able to be realized.

Johannes Bircher offers a model of health that is not directed at equality of opportunity like Daniels, but is instead focused on promoting health in order for an individual to meet her future oriented goals or needs.[87] Certainly promoting equal opportunity or responding to individual needs are not necessarily in strict opposition to each other, nor or these the only two possible objectives of health care. We might hope that by attending to individual needs we also support equal opportunity produced through attention to individualized needs. Or we might be most concerned with equal access to health care, regardless of need. Or we me might be most concerned with minimal or maximal limits for individual or population health care spending and resources. The many ways we can theorize health in order to theorize health justice reinforce why I take focusing on practices and values of care as more fruitful than focusing on health in order to arrive at a view of just health care.

But I think it is worth reflecting on Bircher's dynamic conception of health, because of how it informs care. According to his dynamic conception of health, an individual's needs in life, and the resources available to meet them (and, I would want to add, to meet her future goals as well) are at least partially a product of the circumstances into which she is born, and therefore out of the individual's own control.[88] Bircher assumes that individuals have greater control over and responsibility for their own circumstances across the lifespan. Although he allows for some exceptions to this,[89] I do not think his view sufficiently incorporates structural forms of oppression that practically limit individual agency, even when the individual supposedly matures out of their initially unchosen circumstances.

Despite my noted reservations, Bircher offers a plausible functional conception not of health, but of health care. As already discussed, a focus on health places responsibility, as well as blame, on individuals for their health status and outcomes. Creating pressures on individuals to be independently responsible for an ideal level of health does not account for context, constraints, and realities, and which disregards social engagements, opportunities or restrictions. This does an injustice to individuals, rather than promote justice. Yet a focus on care may be more agile at overcoming these injustices.

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[87] Bircher, 336.
[88] Ibid., 337.
[89] Ibid.

On Bircher's view "society must assume a greater level of responsibility" for some members, "by giving medical, technical, and social support."[90] He allows that "even for adult persons," which I take to mean reasonably capable adults, "society must assume some degree of responsibility."[91] While I would expand his list to be more inclusive of who warrants support, develop an inclusive definition of who is a member of society, and suggest that justice potentially requires more than merely "some" degree of responsibility, Bircher importantly includes not only medical but also technical and, critically, social support in his social support model. We still need to resist too narrowly including only a certain picture of social cooperation as forming the moral community. It is helpful to recall Kittay's critique of social cooperation and the exclusion of those who are most dependent from this picture when analyzing Bircher's proposal.

Yet similar to my worries regarding conceptions of care, we should also exert caution regarding accounts of dependency that merely provide alternative naturalistic arguments from those of Daniels, for example, and his portrait of normal species functioning. They too are reconstructing what is species typical in their own way (from a view, for example, that infancy is the first instance of dependency from which we can make broad inferences about humankind and the content of care). Even if these premises are drawn from empirical observation, a philosophical lens can challenge how the data are interpreted. Instead of inferring that such observations inform the moral practices we ought to adopt, we might, for example, recognize that we are always already entered into practices, which shape and can be shaped by the community of practitioners. This is to say that in my view, we should take practices of care to be those that arise out of contingent realities, including the practices of health care. These practices do practical and normative work, and can be endorsed, revised, or abandoned. Such practices create our nature, not merely reveal it.

To return to Bircher's account, his emphasis on addressing the "cumulative consequences of health determinants"[92] allows for expanding beyond medical, technological or social support, and building into health care other components of care that may be economic or structural. While one's normative definition of health that gets filled in when advocating for a right to health might involve other kinds of social and economic determinants of health, the rights to these other goods are primarily understood as stand-alone, complementary, rights. A right to health care can encompass inputs from a variety of conceptions of health, and work toward each of them concurrently,

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[90] Ibid.

[91] Ibid., 338.

[92] Ibid., 339.

understanding medical access, social standing, and economic sufficiency as all companion elements of care necessary for successful health care.

Daniel Engster provides an account that justifies the value of health care through its function of care.[93] Ultimately, his account focuses on care for the wrong reasons, but there is much to learn from it. Engster retains the centrality of health and separateness of medicine from other forms of care, while also arguing for a more central role for the concept of care. He takes on the problem raised by Daniels and others: once we recognize the role of social determinants of health to overall health outcomes, regardless of access to health care, how can we continue to defend publicly funded health care? Engster argues that we can defend health care due to the moral role of care as justified by care ethics.[94]

According to Engster, health care can be serve to minimize "pain and suffering" and support "a decent level of social functioning" and "quality" in daily living.[95] Engster takes health care to be identical to medical care, defining it as "primarily care, specialist care, acute or hospital care, mental health care, rehabilitative car, and primary and secondary preventative services such as screenings and immunizations."[96] He explicitly excludes features that get grouped as social determinants of health such as "sanitation, water chlorination and health education campaigns."[97] His view of health aligns with that of Daniels, as normal species functioning and the absence of pathology.[98]

Engster believes it is possible to defend health care as a public good on which public funds should justly be spent because health care, even when it cannot restore normal species functioning or remove pathology can respond to a "moral duty to relive the suffering and facilitate the functioning of individuals when we can do so at relatively little cost to ourselves" and this is in part because "we would want such care for ourselves in similar circumstances and can recognize the moral force of helping them."[99]

It is specifically within the scope of medicine to provide this care, rather than family or friends, says Engster, because there are "different forms of care" and can provide more effective

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[93] Engster, Daniel. "The Social Determinants of Health, Care Ethics and Just Health Care." *Contemporary Political Theory* 13, no. 2 (2014): 149-167.
[94] Ibid.
[95] Ibid.
[96] Ibid.
[97] Engster, 150.
[98] Engster, 150.
[99] Engster, 159.

palliative or rehabilitative care, for example, than non-medical caregivers.[100] In other words, medical care is a unique, and specialized, form of care that is valuable as such, separate to or in tandem with more "intimate" forms of caring from family and friends. While Engster does much useful work to center a justification of health care through its function to care, he also reproduces problematic dichotomies between medical care and non-medical care; professional and private care; and intimate and non-intimate care.

Medical encounters can be intensely intimate. Richard Zaner uses an example from Eric Cassel to analyze the phenomenology of the clinical encounter in which Cassel recounts:

> I remember a patient, lying undressed on the examining table, who said quizzically, "Why am I letting you touch me?" It is a very reasonable question. She was a patient new to me, a stranger, and fifteen minutes after our meeting, I was poking at her breasts! Similarly, I have access to the homes and darkest secrets of people who are virtual strangers. In other words, the usual boundaries of a person, both physical and emotional, are crossed with impunity by physicians.[101]

The medical provider might also be providing care that is not narrowly medical, but reaches beyond mere medical technology when she exhibits care through attention, representation, and affiliation with a patient, as discussed in the previous section. That the medical provider accompanies a patient in her journey is a component of care that is not unique to her role as physician, but may be occasioned by it. Finally, there are numerous instances in which the provision of medical care is contingent upon other kinds of care, social, economic, and intimate, being present preconditions for the success or provision of medical care. For all these reasons, health care is not only medical care in a narrow sense (or only professional care, or only public care). To justly and adequately provide health care, many more forms of care are necessary, not only parallel or complementary, components.

So far in this chapter I have surveyed some core concepts of care and strengths and limitations of various approaches to an ethic of care. These include limitations faced regarding public-facing and institutionally accountable care; and questions regarding the relationship between care and justice. I have also discussed definitions of health care that, whether motivated by health or motivated by care, equate health care with the provision of medical care or very narrow social

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[100] Engster, 160.

[101] Cited in Wiggins, Osborne P., and Michael A. Schwartz. "Richard Zaner's Phenomenology of the Clinical Encounter." *Theoretical Medicine and Bioethics* 26, no. 1 (2005): 73-87, 83.

supports in instances in which medical care has nothing more to offer an individual. By presenting and critiquing approaches to both health and health care, I have begun to suggest features that ought to be present in what I am calling "care justice," and to suggest that health care ought to subscribe to this kind of care justice. My challenge now is to expand the concept of health care motivated by care that attends to justice.

Because I focus on care within health care, and I understand care as a normative practice, one that coheres and reflects moral community, health care is also a normative practice that shapes the moral community. Participating in the moral community entails both individual and institutional accountability and responsibility for care, and health care. Here I establish health care, like care, as both a value and a practice. In subsequent chapters I argue that health care within a certain account of moral community is also a right, that entails corresponding duties. However, the definition of health care to which we have rights and responsibilities is distinct from traditional accounts of health care as primarily that which promotes health or that which dispenses medical services.

According to my definition, health care entails much more than mere medical care. When health care is divorced from any one particular account of health, its scope can open up and accommodate a range of ideals about health, being healthy, and well-being. This is not to say that medical care needs to widen its scope to accommodate different values of health into the practice of medicine, though medicine is often adept at working within a plural society and arriving at reasonable solutions to diverse stakeholders.

We see this in what are now archetypal cases in bioethics literature regarding patient refusal of standards of care for religious reasons, for example (a medically indicated blood transfusion, or a medically indicated pregnancy termination to save the life of the pregnant person carrying a non-viable fetus). Or, in other typified cases, patient families wish to pursue aggressive life sustaining therapies for their loved one when medicine has deemed such treatment medically inappropriate on a person who is, save for the artificial ventilation and circulation, brain dead or whose illness is non-survivable. In a sense these are standard, not hard, cases because they rehearse familiar, and established, patterns.

Without getting into the details of the patients, their social contexts, their personal histories, and their religious or other values, we can already fill in some details about what medicine will and will not do in these situations. Medicine will likely assess the capacity of the patients refusing treatment, and if they are found to have the capacity to make these particular medical decisions, and they appear consistent with their values and beliefs, they will be honored. In an emergency case when medical providers know no details about these patients' values and beliefs, and cannot solicit them from the patient or a trusted surrogate, they would act on a medical standard of care and provide the recommended treatment.

In the situation of a family not wanting to withdraw mechanical ventilation and circulation in a brain-dead patient, medicine would not continue to provide these treatments deemed medically inappropriate, but would work with the family to arrive at mutual understanding and, ideally, a compassionate timeline for the withdrawal of these devices. My point is not that expanding the notion of health care requires medicine to act in ways that are inconsistent with the values and practices of medicine in order to show care to patients and respect plural conceptions of health and well-being. Medicine ought to act according to its internal norms and practices, which are often related to evidence-based standards of care.

Yet health care, as I keep suggesting, is more than merely medicine, and this is where expansion can and should occur. Medical technologies, treatments, and access are just one, albeit significant, component of health care. But as has become more and more evident, medical care is not the only, or even the most, important factor on overall health outcomes. This leaves some worried about how and why to justify providing medical care. It also produces the thoughts that medical care is still valuable even if not exclusively valuable to health, and that medical care is valuable because it provides care. Moreover, care supports health, even when it cannot restore (one's ideal conception of) health.

These worries and responses expect health and medicine to do too much, and care to do too little. To point to the social determinants of health as illustrating deep, structural, social features that medicine cannot address is to overlook the ways a more robust conception of health care could respond to these problems through medical practice and social practice. Furthermore, for health care to be effective, it needs much more care built into practices that surround the medical practice. Though we might wonder: why justify this care by expanding the concept of health care? Could we not retain a narrow view of health care as identical to medicine, and still support enhanced social packages of goods that attend to the various kinds of care, the presence or absence of which often influence one's medical treatment and options? And if we expand health care so widely, where are its boundaries?

Continuing to keep medicine separate from an expanded view of health care, and treating social supports as separate, parallel too, or necessary yet different in kind from, medical intervention is the wrong way to think about what is valuable about health care. This thinking overlooks the value of care itself as a social practice, one that I argue, here and in the final chapters, does significant work not just for and between individuals, but also does work to cohere moral communities.

Medicine, as currently practiced, runs up against cases in which its best practice is limited by factors that appear out of its control: a patient is not stably housed and this interferes with the medically indicated discharge plan. Another patient does not need to remain in the hospital and would likely recover much better (physically and emotionally) at home, except they do not have a family member available to provide necessary home-based assistance during their recovery, and therefore they remain in the hospital. Parents of a premature baby hope that she survives her NICU stay after the neonatologists kept alive a preterm infant that without the current standard of medical technology and knowledge would have never survived. But they don't know how they will be able to provide the constant in-home care she will require as she grows older, given their low-paying jobs that they both need to work in order to make ends meet.

Medicine cannot solve these problems. Yet these social features impact any conception of health. Social support services would help, and indeed hospitals engage social workers and case managers to connect patients to available resources. But the resources themselves run parallel to medical care and access, and may not be available to connect to in the first place. While social services often work in tandem with medical care, they are not always available to patients, even when they are medically necessary. Situations in which social services and supports cannot be secured are hard cases for medicine. In these situations, medicine could act, but is limited in doing so by what are taken to be external, not internal, constraints on medical care.

My suggestion is to recognize that health care is not merely medical care: it requires many other forms of care, and this care ought to be recognized as integral to, and components of, health care, in order to administer just health care. A care framework points to the insufficiencies of allowing individual moral luck, social situation, and a rhetoric of (spurious) individual choice to respond to health care needs. This introduces another worry: that health care as I am describing it becomes all-encompassing and limitless.

With what we know about the social determinants of health, radically expanding the concept of health care risks including all aspects of our social, economic, environmental, and political lives and worlds. In response, we might be inclined to turn to a human rights approach, observing that the package of health care I propose resembles a package of human rights, for example, such as human rights to adequate nutrition, sanitation, shelter, and other goods. However, I will not argue for a human rights approach to health care.[102] Nor do I think that there cannot be reasonable limits.

Responding to a human rights framework, and to Daniels's construct of social supports as limited to those with chronic illness or disability, helps refine the ways in which my own view works within present, but broad, parameters. In part, both human rights and Daniels's approaches are focused on access to tangible goods, and to some extent, to material and environmental conditions. My emphasis is not primarily about access merely to goods, which are often limited resources, or even on material and environmental conditions.

My approach shifts a focus to the relationships necessary to achieve certain goods, like having relationships of care, or having a relationship to a place to live or a relationship to a support system. There are limits to care in different ways they are limits to goods. Care is not an infinite resource, though it is one that we can generate and regenerate differently than material goods. Though care often needs, or works alongside, material goods, which are limited.[103] Some of the goods that would be necessary for comprehensive care are not only limited, but also scarce.

Two things my view does differently than others help mitigate, and also define, limits. I do not suggest that a concrete package of caring, social, or political features necessarily need to be in place for all individuals as pre-conditions of their right to health care.[104] My point in including other kinds of social supports and care and as part of health care is not to say that we need to extend these supports and care to all persons automatically as part of a universal health care scheme (let alone a universal human scheme).

Instead it is to say that when social and care supports present barriers to health care, we need to respond to them as a component of health care, and not react to them merely as a barrier that prohibits one from accessing health care. The objective of my view is to give more latitude to, but also stronger requirement for, addressing these barriers to health care when they arise, because we understand them as integral to the aims of health care itself, instead of separate or parallel to it. These supports are integral to health care that is grounded in the values and practices of care.

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[102] In chapters three and four I spend significant time analyzing human rights and human rights approaches to health. The reasons I give here for departing from a human rights view are in addition to the deeper critique I stage in following chapters.

[103] This is especially true when we think about the ways in which care is often undervalued as uncompensated or undercompensated labor, and this further restricts and marginalizes who has access to care because it is limited to those who have caregivers who can afford to do care work without compensation.

[104] Perhaps ideally these features would be completely and universally available; it is a lovely ambition to strive toward these conditions. However, it is not the aim, nor requirement, for my own program to achieve it.

Furthermore, because it is the values and practices of care within health care that warrant rights to care as part of a (claim) right to health care, my view does not necessarily entail that all social supports and care practices are required as claim-rights full stop. But it does mean that people might be able to make claims on us when their right to health care is not being met due to failures of care. Concretely, what does this mean?

By way of example, there are many situations in which we might imagine someone needing a supportive caregiver at home. Parents of small children, and anyone who works outside the home and has dependents in their household would benefit from having dedicated caregivers inside their home. So would anyone who works many hours a week, whether due to a demanding and prestigious job, or due to cobbling together several low paying and underappreciated jobs. Yet these cases are not ones that generate, according to my view, a claim-right to care. Only cases where there is a clear health care need would generate a claim-right to expanded care resources with correlative duties.

While I believe my view of care and obligations of care give us good reasons to reconceptualize obligations to better support caregiving in social policy and practice, this is an extension, but not the conceit, of my argument. Although I am making an argument to expand the concept of health care, I am also limiting my claims to a concept of health care. So the instances in which care would be a claim-right, with correlative duties imposed on others, are limited to instances where the absence of care is a barrier to accessing just and equitable health care.

This connects to the second feature of my approach that helps rethink limits, which is to move away from thinking primarily in terms of material goods allocation and (re)distribution. When we focus too greatly on the material goods of medical care, we over estimate limits and scarcity, and under estimate opportunities to creatively distribute and read distribute care itself. By taking care to be a centrally organizing value and practice, I intend for moral communities to self-define as moral communities in part through their valuing and practice of care, but also for such communities to define for themselves their practices and limits of care in line with their values. In later chapters I will argue that it is up to the moral community to shape and define its values and practices of care, including reasonable limits to care given the communities particular opportunities, resources, and constraints.

My view of health care encompasses features beyond the provision of medical care as part of the relational and caring role and justification for health care, and I take there to be a strong right to health care in the form of a claim-right (the nature of which I develop further in the next chapter). A reasonable question is who has correlative duties to fulfill a claim right to this kind of health care. My response is not that individual clinical staff are solely responsible, nor is the hospital or medical institution, necessarily.

The obligations I intend to generate are not derived from a duty to rescue. Certainly, a duty to rescue does feature in medicine: a patient in urgent need happens to present in a particular hospital, or in front of a particular physician, and the hospital and physician have duties to respond to that patient's immediate need. But I am not suggesting that the structural forms of care a patient requires fall within the category of needing urgent rescue, nor that the particular clinician encountering her patient's other care needs has a direct duty to "rescue" her patient by directly providing these various additional forms of care.

However, the framework I build in the final chapters suggests that individuals do have obligations to contribute to the rights others have to health care within their immediate moral communities. And as claim-rights, individuals can make claims on their moral community, including on individuals who intentionally contribute to groups with collective sway to address and fulfill such rights. These groups could include smaller socio-political collectives like cities or larger ones like individual states within the US; but may also be specific institutions such as a medical facility. So, although I just said it is not the sole duty of the physician who happens to encounter a particular patient to fulfill all duties generated by an expanded concept of health care, she might have some duties to contribute toward fulfilling rights to an expanded concept of health care as a participant in her social community, and the community of her medical institution. I say much more about the mechanisms for these obligations in later chapters.

Let me engage an example to illustrate what up to now is a rather abstract point: a 20-year old woman is brought to the emergency room of a major medical center in the US by her husband accompanied by her two-year-old daughter. She is discovered to have heart failure due to a congenital heart defect. She meets all medical criteria to be put on the heart transplant recipient list. However, this woman is an undocumented immigrant and does not have access to medical insurance. If she were to have or raise the funds to self-pay then she could still receive a donor heart, but as it stands, she is simply ineligible. For no medically indicated reason, she cannot receive a heart, and she will not survive without one. Medicine has the knowledge and skill to help this woman live a longer life, mother her child, and not die an early death, but is hands are tied by social and political factors outside its scope.

Yet if health care were just, and focused on caring for this woman, as well as her family, we could imagine a system that would not accept the injustice that she happened to be born in a country where she was unsafe and needed to flee, or that she did not happen to be born on US soil granting her access to state-funded health insurance as an automatic US citizen. We could also imagine political solutions that would address this problem: different border policies, or a form of global cosmopolitanism. But these are lofty, distant, and unlikely solutions to an immediate problem of health care justice. And these kinds of health care injustices are not merely the result of undocumented immigration or unjust geopolitical systems.

Let's alter our example: our patient is a 45-year old man with liver disease. He is a recovered alcoholic, though his alcoholism led to the dissolution of his marriage and estrangement from his children to which he was abusive when drunk. He had grown up in a household with an alcoholic abusive father, and learned as a young man to replicate his father's drinking and abuse. His family's withdrawal from his life provided the impetus for him to seek out counseling and addiction treatment.

While he has made efforts to turn his life around now, his liver is still failing and he requires a liver transplant. He would be listed for a transplant, for which he meets all medical criteria. Except that he does not meet the social and financial requirements for the transplant: he does not have sufficient finances to pay for post-operative care at home, and he does not have any available family care-givers who are willing to provide the requisite full-time in-home care that is indicated for successful transplantation.

Because transplant criteria are designed to best shepherd scare resources like donor organs, it is necessary to have a strong post-transplantation care and support system. However, it is also expected that patients have access to this care themselves, among their own intimates, or the financial resources to pay for such care. Is it just that this man, who has made good faith effort to overcome histories of abuse, be excluded from necessary health care? It would not be uncommon to hear discussions around transplant criteria include the thought that he is ineligible for transplant because he has "made his choices," implying he should then live and die by them.[105] Could health care take a more expansive care approach and understand that the social, caretaking, and financial

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[105] And the case is more complicated if this man had not made a good faith effort to overcome his own social history of abuse and trauma, or did not have the resources to do so. I still think care is warranted, unless we think he has acted in ways that should lead us to remove him from our moral community entirely. I don't think this is the kind of care that would justify taking an objective stance.

supports are not requirements for, but requirements of, just health care? Would a logic of care understand these historical, inherited, familial, or circumstantial factors merely as a series of autonomous choices? I don't think it would or should.

Some of the solutions to these problems would come about through legislative change. But I do not mean to imply that legislators taking responsibility for social, political, and economic components of health care are themselves health care "workers." Nor are other members of society health care workers when I argue in chapters five and six that individuals have obligations as members of moral communities toward others within their community to effect institutional change and revised practices. But I would say that they are working toward health care, and doing some of the work of care. I think we can maintain a distinction between those working to provide direct medical care and the need to work toward a caring response to health care, in which we have different roles for meeting health and care needs, but in which we nonetheless each have a role.

Care is a relational practice, and better characterizes the ways in which access to that which supports one's embodied self and conception of health is about access to relational practices. Furthermore, though I agree that care is not so narrowly about caring for one's own as to limit it to the immediate biological or legal family, the vision of moral community I offer places importance on being able to establish inclusive caring practices that expand, but also define, a moral community, and entail individual accountability within collective practices of responsibility and action. For these reasons, an expanded concept of health care emphasizing care can better respond to health care rights than other accounts of rights to health care.

In the next chapter I discuss rights frameworks, and in the following chapter I evaluate two approaches to rights to health or health care that, by focusing too greatly on health, paired with what I assess to be an insufficient approach to rights, cannot address health care justice. This is in part because they cannot reckon with historical injustices. In the fifth and sixth chapters I propose an account of moral community based in the concept of an ethical home as the site of just health care delivery, and return to the specific question of transplantation ethics and care justice.

III

Rights

This project intends to normatively ground rights to, and responsibilities for, health care. In this chapter I first explore the concept of rights, and the correlating obligations that claim-rights entail. Then I consider the concept of human rights against the backdrop of a rights analysis. This motivates an in-depth assessment of the human right to health and health care discourse I will turn to in the next chapter.[1] Here I argue that while there are plausible instrumental reasons for human rights, human rights are not claim-rights. And although human rights discourse is worthy of critique, I take the objectives of human rights to be valuable and worth resuscitating.

By recognizing shortcomings in the human rights approach, it is possible to breathe new life into the objectives of human rights. In chapters five and six I propose and defend an alternative model of rights and responsibilities that addresses the spirit of human rights without the same pitfalls. As should be clear from the first two chapters, my overall focus is on rights and responsibilities for health care in which health care is valuable as a practice of care, not merely as a state of health.

In this chapter I first evaluate rights through Judith Jarvis Thomson's framework of Hohfeldian rights, and several feminist critiques of rights. Then I analyze the concept of human rights. Finally, I foreshadow my analysis in the next chapter regarding a human right to health or health care. I argue that even the most persuasive conception of human rights rest on shaky ground, and that the failure to successfully ground rights the right in a human rights framework erodes at the possible obligations such rights entail. There may be instrumental reasons to uphold a notion of human rights. But the instrumental gains are compromised when their intrinsic justification remains in question.[2]

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[1] At this juncture I use the terms human right to health and human right to health care interchangeably, as both views are reflected in the literature. Although some believe that a distinction between health and health care is immaterial for discussions of human rights to either (see Hassoun, Nicole. "The Human Right to Health." *Philosophy Compass* 10.4 (2015): 275-283: 277), I have already argued in the first chapter for a relevant distinction between health and health care.

[2] Hassoun, for example, surveys some of the literature on human rights to health and concludes that "although the skeptics have some good points, there is reason to take seriously human rights to health and health care in theory and practice" (Hassoun, 281). As I will later discuss, Hassoun's reasons for taking human rights seriously focus more on their practice, rather than the theoretical justification for normatively

In the next chapter I analyze human rights to health or health care, as well as the possibility of rights to health care through a right to bodily self-ownership. I evaluate both of these approaches as ones in which rights to health or health care arise out of understanding rights or bodies (or both) as goods that are owned, and reject both approaches for this reason. In the fifth and sixth chapters I propose and defend an alternative model for rights to, and importantly responsibilities for, health care. Because I am most concerned with a claim-right to health care, I view responsibilities as closely connected to a right to health care. A claim-right to health care entails correlative duties to protect, respect, and fulfill such rights.

What Rights Are

The rights literature frequently turns to Wesley Newcomb Hohfeld for an analytical approach to rights. In this section I address analyses of Hohfeld's distinctions by Thomson and Lawrence Becker. Then I consider one critique of broad rights discourse from a feminist approach, specifically in the work of Wendy Brown and Iris Marion Young. These critiques are especially relevant to human rights, including human rights to health care.

Thomson tells us "to have a right is to have a kind of moral status."[3] Selya Benhabib describes the ways in which moral status is recognized by rights as the right to have rights.[4] The question then is what kind of moral status rights imply. Thomson turns to Hohfeld for his analysis of rights, claims, privileges and powers. For Hohfeld "a right is the 'correlative' of a duty - by which he meant that X's having a right against Y to the obtaining of a certain state of affairs is equivalent to Y's being under a duty toward X, namely the duty that Y discharges if and only if the state of affairs does obtain."[5] In other words, rights conceived as claims entail that someone or something has a correlative duty to fulfil the right. Duties held by others guarantee a state of affairs that ensures rights are respected. It is crucial that rights-as-claims (or more simply, claim-rights) impose duties on

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grounding these rights. As I later argue, their utility as political, civil or activist tools, does not render them claim rights with the normative force of such rights without further theoretical scaffolding.

[3] Thomson, Judith Jarvis. *The Realm of Rights.* Cambridge: Harvard University Press, 1990, 38.

[4] Benhabib, Seyla. *The Rights of Others: Aliens, Residents and Citizens.* Cambridge: Cambridge University Press, 2004.

[5] Ibid., 38.

others.[6] Someone or something is responsible for the state of affairs that corresponds to the free exercise of one's rights.

But these correlative rights and duties only obtain to rights "in the strictest sense," and as Thomson notes, claims do not apply to all the ways in which we might deploy the term "rights" in routine speech. "Rights" might also signal "a privilege, a power, or an immunity" in the words of Hohfeld.[7] Thus rights-as-claims are distinct from other forms of rights that correspond to privileges, powers, or immunities. Thomson acknowledges a shortcoming with the term "claims" insofar as it suggests the act of "actually having made some claims" against someone else, rather than merely a term for the strictest sense of rights holding.[8] It is plausible (and likely) that one has rights that they have not expressed as claims on others. Thus, Thomson invokes the term "claims" to mean "a right that an entity **has against an entity** [emphasis in original],"[9] and underscores how her definition neither requires that all rights holders are humans, nor does it entail any particular qualities regarding what kind of entity can have correlative duties.[10]

That rights entail claims does not guarantee claims will be met, or rights fulfilled. Yet rights should to be more than aspirational. James Nickel identifies three features required of rights that they are: high-priority, definite, and binding. Though he adds that "a right is not a perfect guarantee," and allows for prima facie rights to be overridden by competing claims, or the mere inability to meet a claim's demand.[11] On Nickel's account, rights have "specific beneficiaries and addressees,"[12] yet their content varies "greatly in degree of specificity."[13] Highly abstract rights might be more correctly characterized as "high priority goals" unless they can be "made concrete in particular cases."[14] I will return to this distinction between rights and goals in the next section when discussing duties, and then in direction connection with the problem of human rights later in this

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[6] Or possibly the self, Thomson does not rule this out, though cases in which we have claims against ourselves might be rare (or odd). Ibid., 42.

[7] Ibid., 39.

[8] Ibid., 40.

[9] Ibid., 41.

[10] Ibid., 42. Lawrence Becker echoes a similar view of the possibility for non-human-entity rights, with some important additional distinctions. He notes that 'a rights-holder may be either an individual [human or not] or an institution" but a "mere aggregate of individuals should probably not be regarded as a holder of rights." Becker, Lawrence. *Property Rights: Philosophical Foundations.* New York: Routledge, 1981, 9.

[11] Nickel, James. *Making Sense of Human Rights*. Berkeley: University of California Press, 1987: 18-19.

[12] Ibid., 18.

[13] Ibid., 19.

[14] Ibid.

chapter and in the next.

Distinct from rights are privileges, which are "weak" for they are a "mere negation of – thus the lack of – a duty."[15] A privilege in the Hohfeldian sense is not an entitlement as we colloquially use the word. It is something that we might freely do, but have no guarantees that we can or will do, because no entity has a corresponding duty to bring about the state of affairs for the privilege to come to pass. So, if health insurance in the United States is a privilege (in the technical sense, but also as it happens, in the colloquial sense) then it does not entail any duty on another individual or institution to guarantee one's access to health insurance.

According to Thomson, a liberty would require not only what is required of privileges – an absence of duty and therefore a privilege against all, but liberty also entails "that everyone else is under a duty toward [the one with the liberty] to not interfere with [their action in an] appropriately chosen set of ways."[16] Thomson takes this to be a much stronger notion than privilege: it does entail some set of duties. These duties might be characterized as duties of non-interference, or negative duties, in order to ensure a form of negative liberty. However, liberties still place fewer demands on others than do claims, which might require some combination of both non-interference and action. Put differently, claims protect both negative and positive rights or freedom. Liberties only protect negative rights and negative freedom.

Finally, in the taxonomy of rights, rights containing other rights take their own special form as "cluster-rights," which are not as strict as claim-rights because each right within the cluster may or may not correlate with a duty.[17] Therefore it is possible to have cluster-rights that include both claims and privileges. Such a cluster cannot be said to be itself a claim-right with one clear correlative duty. Though the discourse around human rights is diverse, many conceptualizations of human rights that I discuss later in this chapter and in the next appear to be cluster rights. If human rights are cluster-rights, then can human rights entail clear duties? When taken individually, is each right within human rights itself a claim? Or are some privileges and liberties? If each is a claim, according to the logic of cluster-rights, it might be necessary to disassociate the cluster of human rights from each other in order to single out each individual claim-right that does entail correlative duties within human rights.

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[15] Thomson, 46.
[16] Ibid., 54.
[17] Ibid., 55-56.

What Duties Are

If the "moral significance of having a right is a consequence of the relations between rights and duties"[18] then we need to get clear about what duties are, and what they are not. It is a mistake to understand duty merely as anything entailing an "ought." There are many things we "ought" to do that we do not have a duty to do insofar as no one can make a claim against us to do so. We often use "ought" for what it might be good, but not required, to do. This is true of the category of the supererogatory. I ought to do a favor for someone I care about, especially when it is of little to no burden on me, but it would cease to be a favor if I was under an obligation to do so. Thus, a duty is stronger than an "ought." It is instead a concept that "attaches to two people," or we might say two entities, where there is always "one who is under the duty and the one toward whom he or she [or it] is under it [the duty]."[19]

For Hohfeld, any "duty" might be taken to be a "legal duty," which would therefore correspond to the jurisprudence under a particular legal system.[20] Thomson notes that in this case, Hohfeld has created a theory of legal rights, not moral rights.[21] Whether rights are legal or moral, they will be indexed to the operative system of law or morality within which one lives. Just as there are various theories of law, there are various theories of morality, and they each potentially yield their own sets of, and groundings for, legal and moral rights, respectively.[22]

Thomson, who takes her focus to be on moral rights, including life, liberty, and property, suggests that legal and moral rights might not be parsed out as "two distinct species of the genus rights." Instead it is best to understand that some rights will have both legal and non-legal sources.[23]

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[18] Ibid., 60.

[19] Ibid., 62.

[20] Ibid.,72.

[21] Ibid.,73.

[22] Becker suggests that legal rights depend on the recognized system of law but leaves the distinction between natural law and legal positivism as an open question; Thomson takes a decidedly legal positivist approach to legal theory. I will largely follow the legal positivism approach with Thomson and will understand the law to be primary and secondary rules established by an institution according to the theory of H.L.A. Hart in *The Concept of Law*. Oxford: Oxford University Press, 1961. Further, Becker draws two distinctions within moral rights theory: one is the "conditions under which a right-claim may be said to be sound" (9-10) and the other is the question of who has the status to enforce a right (11). Becker notes that Hart would consider additional distinctions between moral and legal rights including specifications for "excusing conditions appropriate remedies, and methods used to extract obligations" but that these additional qualifications are not always the case for moral obligations, and thus these may in practice differ between legal rights and moral rights, but for Becker they do not comprise the contents of what distinguishes between the two (Becker, 17).

[23] Thomson, 73-74. Perhaps at best, though, we might hope that legal rights will always have moral sources.

Moral rights, as Becker says, can be "private or not, legal or not, natural, human, or special, primary or secondary" and can "involve any one or any combination of the rights-relationships described as claims, liberties, powers, immunities and recipient rights."[24]

On this view, moral rights can encompass other kinds of rights. A potential problem with moral rights, however, is their level of abstraction. As already noted, Nickel describes rights as addressing specific respondents to claims. When rights are overly abstract they may not "always imply clearly what must be done and by whom."[25] Whereas legal rights make precise claims with specific agents bound to meet them according to the terms of the law, moral rights do not necessarily invoke clearly defined duty-bound agents, nor prescribe modes of recourse for claimants whose rights have not been respected.

The human rights literature rehearses a debate regarding whether human rights are distinctly or primarily legal or moral rights, and what kind of legal or moral rights they might be, that is, according to which theory or theories of law or morality. There are accounts of primarily legal human rights to health, as codified by international law, and reflected in the United Nations definition of a human-rights based approach to health as one in which "development efforts are anchored in a system of rights and corresponding State obligations established by international law."[26]

While there may be a moral ground for such legal rights, these rights are construed as binding states as the agents accountable to legal human rights. Such rights are intended to have legal weight.[27] A moral view of human rights can still accommodate that human rights can do legal work, by understanding the moral and legal realms to be in a mutually reflective relationship.[28] Yet on this account, the moral rights of human rights are doing interpretive work to arrive at legal rights, while the legal rights are the ones with correlative duties. A third approach views human rights as both

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[24] Becker, 17.

[25] Nickel, 19.

[26] United Nations Office of the High Commissioner for Human Rights and World Health Organization, "A Human Rights Based Approach," accessed November 25, 2018 https://www.ohchr.org/Documents/Issues/ESCR/Health/HRBA_HealthInformationSheet.pdf

[27] Though this legal weight falls within the realm of international law, which leads to other questions about jurisdiction and mechanisms for accountability under international legal systems.

[28] Griffin, James. *On Human Rights*. New York: Oxford University Press: 2008, and Nickel, James. *Making Sense of Human Rights*. Berkeley: University of California Press, 1987.

moral and legal, but not in a reflective relationship with each other.[29] On this account, legal and moral human rights are distinct, and not in direct relation to one another.

Sourcing human rights in legal or moral rights entails different duties and different duty-bound agents. Critics cite problems with attributing or allocating duties as reason to reject human rights frameworks,[30] while others question whether human rights frameworks impose any positive rights for which agents are responsible.[31] Conceptualizing human rights as primarily or distinctly legal or moral, suggests Nicole Hassoun, depends "on one's underlying philosophical commitments and/or the project one is interested in pursuing."[32] If human rights are a cluster-right, as I suggested, then the distinctions between moral and legal rights might be gratuitous, for their content and justifications have pluralistic sources with various corresponding duties. Nickel holds a view sympathetic to this, suggesting that while governments are the standard bearers of human rights duties, individuals also have obligations to uphold human rights and to pressure their governments to do so.[33]

Arguably there are multiple routes to a correct conclusion that there are holders of human rights, and agents obligated to fulfill human rights claims, if this conclusion can be proven correct. As I discuss, the many justifications for human rights, the various axes according to which they function, and their plural or cluster nature, present intractable problems of application: both in terms of recognizing rights-holders and rights-enforcers. My view is that these problems of application do not nullify the intent of human rights, and the values that they express regarding minimally decent lives, obligations toward others, and what we ought to expect and demand from those with whom we share in moral communities.

Yet these problems require us to rethink whether traditional human rights frameworks are sufficient to respond to the health and health care needs of ourselves and others. With this problem

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[29] Buchanan, Allen. *The Heart of Human Rights*. New York: Oxford University Press, 2013.
[30] O'Neill, Onora. "The Dark Side of Human Rights." *Contemporary Debates in Political Philosophy* edited by Thomas Christiano and John Philip Christman. New York: Wiley-Blackwell, 2009 and Sreenivasan, Gopal, "Human Right to Health? Some Inconclusive Skepticism.' *Aristotelian Society: Supplementary* 86 (2012): 239-265, for example.
[31] Robert Nozick has a version of the view that political rights guarantee negative liberties and do not entail positive rights that would include social or economic goods, including health care goods. Nozick, Robert. *Anarchy, State, and Utopia*. New York: Basic Books, 1974.
[32] Hassoun, 275.
[33] Nickel, 41-42. Though this obligation on the part of individuals cannot be in the form of specific claims on individuals, at least as far as Nickel has presented the nature of the obligation. My approach in later chapters aims to strengthen individual obligations that can be generated by claim-rights in order to meet others' claims.

in mind, I argue we can reject human rights approaches in favor of other, more actionable, rights frameworks. In the next section I turn to property rights. I understand property rights to be a central mechanism for understanding other kinds of rights, and argue for this point in more detail in the next chapter. By illustrating the operative mechanisms for, and problems with, property rights, I am building toward two key premises regarding my overall arguments about rights.

The first premise is an observation, that I expand on in the next chapter, that two kinds of property rights or models of ownership underpin certain accounts of rights and access to health or health care. The second premise, which I turn to now, is that the institution of property rights itself is an historically unjust one. Even if it is possible to justly transfer property once acquired (and I take it that it is, according to a positive law approach as I discuss), the initial acquisition of property is always unjust. The various mechanisms for establishing initial ownership all fall flat.

My point is not to reject all forms of private ownership. However, I worry that modeling other kinds of rights on property rights will perpetuate injustices in how we recognize and fulfil rights more broadly. Moreover, I take it that while we can still own things, given the historical injustices of property ownership, when we do come to presently (and presumably justly) come to own goods, we might have much greater obligations to share that which we own.

I now turn to property rights, and then I move to feminist critiques of rights more broadly, before returning to human rights in more detail. In the next chapter I consider human rights applied to health and health care, as well as self-ownership models of rights from a libertarian tradition. There I consider what happens to health care when owning is connected to the source of rights.

Private Property: Natural and Positive Law Approaches

Much of the literature on private property turns to John Locke and his *Two Treatises on Government* for a foundational analysis.[34] According to Lock, there are two senses of property: ownership and that which is necessary for commodious living, which includes one's livelihood.[35] For Locke, unlike Thomas Hobbes, you do own property in a state of nature, and you enter into civil society in order to protect it.[36] Additionally, all men are born into a state of perfect freedom and

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[34] Locke, John. *Two Treatises on Government.* Cambridge: Cambridge University Press, 1988.

[35] Ibid., 268.

[36] Ibid.

equality as per natural law.[37] Furthermore, there is a connection between property and propriety, such that property is that which facilitates life, not simply the material items which one controls, as part of a universal right to self-preservation.[38] Self-preservation could include taking ownership of that which one appropriates through use, such as the food one consumes.[39]

Liberty, which is a universal right, does not entail license, which is separate,[40] and it is both a universal right and obligation to enforce natural laws and right,[41] including the preservation of the self and mankind. These rights justify, according to Locke, the ability for an individual to punish one's offender.[42] Thus even prior to "agreeing together mutually to enter into one community," which puts an end to the state of nature in order to "make one body politick," individuals are already afforded natural rights to property, including the right to enforce the claims that such a right would entail.[43] Civil society and the social contract are constructed as safeguards to further these rights and protections, not to establish them.

According to Locke, there are two means of establishing property ownership. One is through appropriation or use, such as the consumption of food,[44] and the other is through labor, since the work of one's body belongs to the individual and thus the labor one "joins" with other elements makes them one's own.[45] Locke imposes reasonable limits on what one can appropriate, or join with labor and thus own, by noting the condition that ownership is permissible "at least" when enough and as good is left for others.[46] Property is limited to that which can be enjoyed (i.e. used) and therefore is not what can merely be amassed and left to spoil.[47] Grotius also saw use as a necessary condition for property ownership and connected use of consumables like clothing or food

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[37] Ibid., 269. This view of the individual is one that might need to be troubled, as a highly atomistic view of the self that does not acknowledge how one is always already thrown into particular situations, systems, and likely systems of structural inequality – as evidenced by Locke speaking to all *men* having perfect freedom and equality. I don't take this to be a rhetorical stand-in for all of humankind, but to indeed reflect the rights of *men,* and likely particular men. However, for the purposes of Locke's analysis, I will leave further critique aside.

[38] Ibid., 271.

[39] Ibid., 286.

[40] Ibid., 270. This view of "liberty" should not be confused with Hohfeld's sense of "liberty" discussed earlier with regards to a taxonomy of rights.

[41] Ibid., 272.

[42] Ibid., 274.

[43] Ibid., 276.

[44] Ibid., 286.

[45] Ibid., 288.

[46] Ibid.

[47] Ibid., 290.

to the occupation or habitation of territory, suggesting that: "a thing that cannot be occupied cannot become property and remains open to the common use of everyone."[48]

At first glance, these restrictions might appear to place a great deal of constraint on acquisition. However, it is worth noting that the civil society that codifies and protects property rights in Locke's schema also participates in a market where goods can be monetized. Jeremy Waldron describes a route to override the spoilage proviso by transferring goods that are perishable for those that are not (such a money).[49] It is, in Waldron's words, "market exchange," which "explains how I can come to have more in my possession than I could possibly have labored [*sic*] for."[50]

Furthermore, under Waldron's analysis the "enough and as good" clause of Locke's *Treatise* is neither a necessary nor sufficient condition for property ownership. If it were, it would apparently render most property ownership null and void under contemporary conditions in which certain territories have such a high population density that it is impossible for each person to have enough and as good left for their own use. Instead, Waldron takes Locke's phrase not as a "restriction or a necessary condition on legitimate appropriation" but rather a case in which one cannot be questioned in their right to appropriate property when there is enough left for others.[51]

Waldron highlights the ambiguity of Locke's use of "at least where" there is enough and as good for others, which appears to be a "**sufficient** condition [Waldron's emphasis]," rather than a stronger, necessary conditions such as "only if" or "as long as" enough and as good remains.[52] Waldron is not reading Locke to suggest that land must remain in common for the appropriation of private property to be valid. Instead, Waldron takes it to mean that at the time in which Locke was writing some land did remain in common. The fact of commonly held land implied that anyone could have equally taken up acquisition of such land and therefore cannot complain "about the subsequent prosperity of those who did."[53]

This formulation presupposes a truly egalitarian distribution of capacities such that it is in fact possible for any individual to have equal access to the acquisition of lands had he or she wished

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[48] As cited in Pateman, Carole, and Mills, Charles. *Contract and Domination.* Cambridge: Polity Press, 2007, 48.
[49] Waldron, Jeremy, "Enough and as Good Left for Others." *Philosophical Quarterly* 29 (1979): 319-328, 322.
[50] Ibid., 323.
[51] Ibid., 321.
[52] Ibid.
[53] Ibid., 322.

to acquire them. It also implies or assumes a shared vision of the value and role of, or the very possibility for ownership of, private property. In reality this might not be a universally held value – it is particularly brought into question by historical relationships between colonizers and indigenous populations, including in the United States.[54] However, Waldron is not making a case for the justness of Locke's schema for property acquisition. He is merely establishing distinctions between the necessary and sufficient conditions that are or are not in place for a Lockean account of private property and territorial acquisition.

There are a variety of other critiques and clarifications of Locke's conditions for ownership in the literature, one I will note in passing, and two of which I will explore more fully below. These critiques are non-exhaustive, but they capture the types of challenges to a Lockean account of property the literature supports, and which constrain the analogy between property and territory.

Robert Nozick offered an absurd example to undercut Locke's "mixing" criteria for the appropriation of property, asking if he owns a can of tomato soup and dumps it into the ocean, does this mean that he now owns the sea?[55] There are at least two ways in which Nozick's thought experiment does not track onto the Lockean program. One is that it is unclear what labor is being mixed with the land in this example, other than opening the can of soup and holding it to pour. It appears that Nozick is allowing for the prior ownership of the can of soup to do the work of productive labor. The other is that for Locke the mixing of labor with land is a means of adding value to the land. This is done by improving it, or making it more productive through cultivation (and thus offering a good not only for the self but potentially for humanity).[56] In Nozick's imagined scenario no value is added by adding tomato soup to the ocean, and arguably such mixing could be a harm – a form of pollution.[57]

However, Nozick's absurd challenge to the Lockean model of property does point to how quickly questions arise regarding the foundational assumptions inherent in Locke's account. Carol Rose underscores a puzzle for the original acquisition of property necessary for ownership: Locke's

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[54] Dodds, Susan. "Justice and Indigenous Land Rights." *Inquiry* 41.2 (1998): 187-205; Pateman, Carole, and Mills, Charles. *Contract and Domination.* Cambridge: Polity Press, 2007; Stilz, Anna. "On Common Ownership." *Ethics and International Affairs* 28.4 (2014): 501- 510.

[55] As cited by Carol Rose in Rose, Carol M. *Property and Persuasion*: *Essays on the History, Theory and Rhetoric of Ownership*. Boulder: Westview Press, 1994, 11.

[56] Locke, 294.

[57] Unless by some chance the wildlife population in that portion of the sea happened to thrive on canned tomato soup, which is an imaginable, but unlikely, possibility.

proposal for the mixing of labor to create property on the basis of desert nonetheless requires a pre-existing theory of ownership.[58] Even if the right to property is granted as part of natural law, the idea that mixing labor creates property appears to be a theory of ownership that is either an interpretation or extrapolation of natural law.

As Thomson observed, "the world was not created with its contents already owned: ownership has to be **acquired** in some other way [her emphasis]" that does not rest on the assumption of prior ownership.[59] Yet Locke's account of adding value to something is not sufficient for establishing ownership over what was not previously owned. Thomson rightly asks: "why not conclude that, thanks to the labor-mixer, something still unowned now has more value than it formerly did?" For Thomson, the idea of a desert-based rationale for ownership is not sufficient to actually entail ownership.[60] Similar to Rose, a further account is necessary.

Rose and Thomson both offer potential paths out of these puzzles of ownership and original acquisition. Rose suggests that a common law approach would share certain features of both a labor and a consent theory.[61] If "**possession** or 'occupancy' is the origin of property" there remains a problem for what to do about things that are abandoned, lost or found, and a larger problem of what even "counts as possession" or why it would be a "claim to title."[62] Rose instead focuses on the act of taking possession as a "kind of **statement**" or "communication" which is a form of notice-giving that one has taken possession. Stating that something "is mine" is a means to acquire ownership when said in a way that others understand it. The law then protects this ownership from others who might counter-claim that it is theirs.[63] The act of taking ownership is

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[58] Rose, 11.
[59] Thomson, 324.
[60] Ibid., 326.
[61] Rose, 12. The emphases in the text are Rose's own.
[62] Ibid.
[63] Ibid., 14-16. The question of what kind of communication is legible to others, and what happens when one claims that something is theirs in a way that is not understood by others remains a problem for Rose's view that would need significant development. But I think there is something valuable about a program that requires that we make ourselves understood to others in order to claim exclusive ownership and control over goods, and that the burden is in some ways on those claiming the right to ownership to communicate effectively if we assume those claiming ownership are also those who tend to be in positions of power within the society in which they operate. The worry would be when those who are not generally in positions of power, who have been historically marginalized, excluded from rights like ownership, or otherwise oppressed communicate the taking of a claim over something and this is not heard by the dominating power because it chooses to not hear or understand the claims made by the minority or marginalized group or individual. This kind of worry motivates the views I set out in chapters five and six.

expressive and communicative, and understands the agent taking possession to be in relation to all other fellow commoners to whom the act communicates.

The communicative act of taking possession is a form of common law, while at the same time it establishes common law (in the sense that Locke saw the formation of civil society as part of protecting the rights to which each individual is entitled). Communicating property claims means that "others will know that they should deal with me directly if they want to use my property. We can bargain rather than fight; and through trade" property will "come to rest in the hands of those who most value it.[64] Or, as the case may be, it will come to be held by those who are in a position to best express value and claims over the property.

Rose's approach presupposes a society in which every member is both a full member, and has equal voice in expressing claims, or bargaining for property. In practice, under conditions of oppression and exclusion, this may often not be the case. But according to Rose's idea of expression, common law is also a form of positive law, under which the terms of the legal structure are being established through the practices, and codification of those very practices, in the society. The laws in effect are those the society recognizes as in effect.

Thomson takes a directly positive law view of property. She rejects three possible principles for property ownership based on efficiency. One is a "first come first served" principle that would justify adding value as a means to establishing ownership insofar as one wouldn't invest in adding value to something unless one could become the owner of the thing.[65] A second possible approach is that it would simply be efficient to adopt a set of rules for the convention of ownership.[66]

The third approach is a "Jointly-Owned-from-the-Outset Thesis." Thomson eventually reject this idea, only after offering several suggestions as to why this later efficiency argument might be attractive. The view is reminiscent both of Locke's position that all humans have equal right to unowned land held in common, and of Kant's rationale for the common-ownership of the surface of the earth.[67] Thomson provides an imagined analogy to the common ownership of the moon. If the moon is "owned by all mankind in common" then "it is no more plausible to think I have privileges" regarding the moon and its contents "than it is to think I have a privilege as regards you

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[64] Ibid., 16.
[65] Thomson, 329.
[66] Ibid., 333.
[67] Kant, Immanuel. "Toward Perpetual Peace." *Practical Philosophy.* Trans. Mary J. Gregor. Cambridge: Cambridge University Press, 1996.

of painting our jointly owned house red."[68]

However, Thomson asserts that the "Jointly-Owned-from-the-Outset Thesis" is "not a happy idea" for "it is no clearer how private property can have arisen." If property is jointly owned by all of mankind then it is not clear "how private property can have arisen from the unowned, and even less clear if labor-mixing is to do the explanatory work." In other words, "it is hard to see what could have made the Jointly-Owned-from-the-Outset Thesis true."[69] Whether supposed common ownership of the earth is through natural or divine law, it requires an assumed step that there is a power, natural or divine, originally in a position to grant ownership to humankind. The question becomes: who granted this original joint ownership, and how can we know this?

Thomson rejects the Jointly-Owned-from-the-Outset Thesis as false[70] and instead takes the "Ownership-Has-Origins Thesis as true," with a further supposition that "if a thing is unowned, then everyone does have a privilege as regards all others of making use of it," though this privilege is restricted in accordance with Thomson's Limits Thesis.[71] Once it is given that Ownership-Has-Origins, and these origins are not derived from initial common ownership of all things through natural or divine law, a subsequent question follows: what makes property in the first place? For Thomson, prevailing law makes one the owner of her house, based on the recognition and efficiency of such laws. Although it remains possible that a more efficient set of laws could be put in place, as long as ownership is acquired according to transfer through recognized laws, then the current ownership is justified.[72]

This still does not answer the question of first acquisition of property, only current acquisition. An efficient and recognized legal system is a precondition for the acquisition of property, and in this view, property is necessarily institution-based, and cannot be pre-political or pre-institutional. As Thomson points out, natural law arguments for property are misleading as a grounding for the initial acquisition of property. Even though natural law arguments often also appeal to efficiency, to say that "'adopting legal system L would be efficient,' does not yield that we

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[68] Thomson, 335.
[69] Ibid.
[70] This also undermines Kant's premises that ground his views on a form of cosmopolitan obligation to hospitality, based on shared ownership of the surface of the earth, noted above.
[71] Thomson, 336. "The Limits Thesis has the form: X has a claim against Y that Y not do alpha if an only if either (i) X's claim is a pure social claim, or (ii) Y's doing alpha either (a) itself would be Y's committing trespass on X, or causing X harm or non-belief-mediated distress, or (b) is a means by which Y could be committing trespass on X, or causing X harm or non-belief-mediated distress."
[72] Ibid., 337.

already live under L;" similarly "'adopting a set of rules assigning natural rights N would be efficient' does not yield that we already have N."[73] Justifying natural law principles due to their efficiency does prove that such natural principles are true. To suppose that a certain set of natural laws should reflect how property is best to be understood is to derive what should be by assuming what is.

Thomson takes the stance that the "law makes – and unmakes – property" and that it could do so justly, or unjustly. However, it cannot be assumed that property laws are just simply because they are the laws.[74] It remains, therefore, an open question as to whether a legal system in place is just or efficient, but the legal system's recognition as an institution is a necessary condition for any criteria of property ownership. This positive law account is not dissimilar from how Rose treats common law – as acts and then texts that define relationships between persons and property, but also between humans and nature. And these relationships between humans and nature, as well as legal systems and their scope, connect to the larger question of the link between private property and territorial sovereignty, when thinking about statehood and citizen right (as I do in the next chapter).

Thomson returns to the question of ownership over the moon to ask the question of who (or what) can legislate such ownership? "For a particular legal system to be sovereign over a territory is for that legal system to be the law of the territory, governing not merely the behavior of people in it, including those who merely visit or pass through it, but also what uses can be made of it, and what ownership rights can be acquired over, the very stuff of the territory, including the land itself and whatever is on or under it."[75] Paradoxically, for the laws to establish themselves over a territory, there need to be laws in place that legislate what it is to take ownership of such a territory.

Regarding the moon, then, the moon is unowned and no one can "come to own the moon or any of its contents" because there is no legal system that could establish initial acquisition of the moon over such a territory (though one can make reasonable use of it within the constraints of her Limits Thesis).[76] Thomson concludes that her "concern has been only to make it seem plausible to think that it is law, and not nature, that makes property," and that the necessary and sufficient conditions for a legal system to have control over a territory is that such control is "settled" and not "in flux."[77]

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[73] Ibid., 338.
[74] Ibid., 342.
[75] Ibid., 345.
[76] Ibid., 347. See note 69 for the Limits Thesis.
[77] Ibid., 346.

While Thomson persuasively argues in favor of rejecting natural law theories of property, she does not resolve the problem of first acquisition of property to initiate a system of ownership. The convention of property first must be established in order to establish property rights and holdings. The convention of property needs to exist within a territory for a state to claim ownership through the mechanism of property rights over said territory.[78] Rose would have common law express acts and "texts" that establish a relationship between humans and nature, or the land.[79] It is the actions themselves that would assert law, while the law then reflects and constructs the relationships in question.

Ultimately, I think a more relational approach to rights, including the right to property and territory, but also to care and health care, is going to move us in the correct direction. Systems of property rights often fail to acknowledge the ways in which these contingent systems reflect and reproduce systems of structural inequality: those who came to (unjustly) own something in the first place are then in a position to (allegedly justly, based on systems of just transfer of goods) pass on ownership and control to others through inheritance or purchase, privileging those who reap the benefits of injustice while continuing to exclude those (individuals or groups) who were, and continue to be, the victims of unjust acts.

Feminist Critiques of Rights

Before moving to the question of human rights, I will raise several, primarily feminist, rights critiques that prove fruitful for evaluating human rights and human rights to health or health care. Iris Young, in critiquing the framework of a just society offered by John Rawls in his *Theory of Justice,* and the distributive justice positions that have emerged from his concept of justice as fairness, takes issue with the way in which the focus on fairness has been on distribution of goods.[80]

Young diagnoses the "focus on possession" as leading to a tendency to "preclude thinking about what people are doing, according to what institutionalized rules, how their doings and having are structured by institutionalized relations that constitute their positions, and how the combined

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[78] Therefore, a territory cannot be said to exist prior to the establishment of law, which in turn legislates the scope of the territory and its legal systems and conventions.

[79] Rose, 19.

[80] In chapter one I already started to address the ways in which this Rawlsian view has been applied to the just distribution of health care goods, and I will return to it in chapters five and six.

effect of their doings has recursive effects on their lives."[81] In Young's view, this emphasis on goods overlooks the distribution of rights, and particularly "rights that do not refer to resources or things, like the right of free speech, or the right of trial by jury."[82] Rights themselves, says Young "are relationships, not things; they are institutionally defined rules specifying what people can do in relation to one another."[83]

On Young's view, the focus on rights should to be as rights to do, not to have. Young's view of rights recalls basic principles of capabilities approaches. Broadly construed, a capability approach as a normative theory focuses on individual freedom to do, by having capacities for functioning. Martha Nussbaum, in conversation with work by Amartya Sen, has significantly contributed to the philosophical development of capability theory. Nussbaum has characterized capabilities approaches as focusing on two primary questions: those of basic quality of life, and those of justice.[84]

Nussbaum's own view develops a list of ten capacities that she determines are necessary for human flourishing. These include physical capacities of life, bodily health, and bodily integrity; psychic capacities including: senses, thought and imagination, practical reason, and emotions; and social capacities including: affiliation, engagement with other species, play, and control over your own environment.[85] We can reasonable debate the usefulness of an objective-list view (and I think it depends to some extent on our view of well-being, as discussed in the previous chapter). We can also debate the content of an objective list, even if we accept an objective list approach as appropriate. Yet Nussbaum's view is central to the literature, and provides a guidepost for thinking generally about capacities and capability theory.

Essentially, capacities are states of "being and doing,"[86] so when we say that someone "has the capacity" or "has a capacity" this is meant to convey their capacity for functioning, not merely the possession of a capacity. We might say that the focus on being or doing reflects how it is a normative theory instead of descriptive one. That someone has a capacity to walk up a flight of stairs is only relevant to a world in which there are stairs to be climbed. Merely possessing this capacity is neither necessary nor meaningful in a world without stairs.

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[81] Young, Iris Marion. *Justice and the Politics of Difference.* Princeton: Princeton University Press, 1990, 25.
[82] Ibid.
[83] Ibid.
[84] Robeyns, Ingrid, "The Capability Approach," *The Stanford Encyclopedia of Philosophy* (Winter 2016 Edition), edited by Edward N. Zalta.
[85] Nussbaum, Martha. *Frontiers of Justice: Disability, Nationality, Species Membership*, Cambridge, MA: Harvard University Press, 2006.
[86] Robeyns.

So rather than focus on having a healthy body, a capabilities approach reframes this as being in a healthy body. To fully embrace Young's view, we might construct health as a relation to our body, not as a status that one possesses. Yet health care is more complicated. We can understand health care as, among other things: being part of a health care system; being in relation to health care providers; doing the work of caring for one's health such as undergoing treatments, going to the doctor, etc.; and caring for someone else's health. To be or do these things we may also need to have access to or possess other resources in the form of: health insurance; relationships with care providers; the means to pay for medical care and treatment; access to health care systems; etc.

At the same time, there are compelling reasons to take the stance that the material goods of health care, like having health insurance or the right to treatment, should prioritize health care as a relationship, instead of merely a possessed good. In the view I offer in chapters five and six, I respond in part to Young's notion of rights as relations, and argue for health care as a form of relational right. For the purposes of this chapter, rights-as-relationships present opportunities and constraints for the just distribution of human rights, and the very justification and defense of human rights including a human right to health or health care.

Young is also concerned with the ways in which supposed universal approaches to justice fail to recognize the role of social groups and then marginalize and exclude certain groups. She takes feminist moral theory to be a response to an "ethic of rights" in that feminist moral theory takes up particular needs related to social, family and personal contexts.[87] Critiquing the "ethic of rights" is also critiquing the "ideal of impartiality itself, as an appropriate ideal for any concrete moral context," which Young holds "expresses a logic of identity that seeks to reduce differences to unity."[88] A logic of identity that "denies or represses difference" also creates more stark dichotomies between "universal and particular, public and private," and therefore ought not be the ideal for which moral reasoning strives.[89] Rights discourse demands a moral agent translate needs into claims, and Young questions whether claims can encompass the full scope of needs (let alone be responsive to wants and desires) that constitute an individual (or a group). Justice may, therefore, require more than simply attending to claims.

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[87] Young, *Justice and the Politics of Difference,* 96.

[88] Ibid., 97.

[89] Ibid., 98. The tension between universal and particular is one I addressed in the previous chapter with regards to care theory, and to which I will return in later chapters when I present my view of moral community and ethical home.

Capacities approaches, for example, are value-pluralist and can accommodate greater human diversity, including of physical embodiment, social or environmental context, and preferences, when promoting well-being. But they face challenges translating capacities into rights corresponding to a theory of justice.[90] Human rights aim at justice by asserting claims, but may not as easily accommodate difference. If human rights are a shared set of needs among all humans (therefore indistinguishable and impartial from one to the next), then human rights risk overlooking contingent needs of specific, and possibly the most marginalized, persons or groups.

This is particularly true with regard to claims for health care, in which specific kinds of bodies or members of certain groups could have unique health needs not recognized by dominant groups who direct policy and law. Some argue that moral obligations arise out of vulnerability. On Robert Goodin's view,[91] we might observe that because those who direct human rights law and health care policy are generally in positions of authority, their obligations are heightened to those most vulnerable (by virtue of their radical dependency on the outcomes of the actions of those in power) to human rights implementation and health care policy.[92]

Wendy Brown offers another view of how rights are wielded by dominant groups that render rights at least paradoxical, if not oppressive, to members of non-dominant groups. Brown suggests that having particular identities is in conflict with the universal aspirations of rights. She

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[90] See Robeyns. Capabilities approaches do not generate claims with corresponding responsibilities. As already noted, claim-rights entail corresponding duties. Onora O'Neill charges that attributing obligations is essential to theories of justice: O'Neill, Onora. *Towards Justice and Virtue.* Cambridge: Cambridge University Press, 1996. This point is not only a problem for capabilities theories, but also for human rights and who has a duty to take on obligations or responsibilities of claim rights they generate.

[91] Goodin claims that vulnerability and dependency trigger obligations, and that these obligations might be much more expansive than we intuitively recognize. Goodin, Robert E. *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities.* Chicago: University of Chicago Press, 1985. One way to be more responsive to unique vulnerabilities is to engage inclusive practices that solicit perspectives and participation from a variety of stakeholders, including historically marginalized groups, and social justice movements that appeal to human rights tend to aim for this kind of collaborative engagement.

[92] Though critical theories of human rights challenge the power dynamics internal to human rights practice, or instrumental in their creation and implementation. For example, Susan Waltz offers a counter-narrative for the creation of the Universal Declaration of Human Rights in which she challenges the prominence of western great powers in crafting the document, and points to the ways in which contributions from smaller states has been historically overlooked, thus revising the assumed power dynamics of who creates and promotes human rights. Waltz, Susan. "Reclaiming and Rebuilding the History of the Universal Declaration of Human Rights." *Third World Quarterly* 23.3 (2002): 437-448. Cristina Beltrán analyzes the role of noncitizens in making political claims to which they otherwise do not have access as human rights activists challenging the power structure of human rights Beltrán, Cristina. "Going Public." *Political Theory.* 37.5 (October 2009): 595–622. And Karen Zivi reconstructs rights claims as part of a democratizing process: Zivi, Karen. *Making Rights Claims: A Practice of Democratic Citizenship.* New York: Oxford University Press, 2012.

argues that having rights as an identity group is therefore paradoxical. In Brown's example "to have rights **as** a woman is not to be free of being designated and subordinated by gender. Rather, while it may entail some protection from the most immobilizing features of that designation, it reinscribes the designation as it protects us, and thus enables our further regulation through that designation."[93]

Being categorized as a particular group holding rights specific to the group recognizes those rights, doing the work to "empower and make visible" that legal scholars describe as a core function of rights,[94] while continuing to perform oppressive distinctions that exclude or marginalize the group in question from other, dominant, groups. In order to rectify a particular form of injury or suffering produced through exclusion and inequality between groups, rights are extended to the group that do not necessarily rectify the historic insubordination, and might in fact amplify and replicate it.

Holding rights as members of specific groups yields another paradoxical problem: it particularizes the group in question, while it universalizes within the group. As Brown observes, pointing to the "experience of **some** women to represent all women" is one kind of pitfall for this kind of group rights discourse, but on the other hand "remaining so abstract as to capture **all** women but not speak to any particularities **of women**" would represent another, and contradictory, pitfall.[95]

Brown's paradoxical point is apt for the health care context. Efforts to extend rights for health to all may not be sensitive to unique health care needs, such as health care plans that do not attend to the reproductive health needs of those who can become pregnant.[96] Historically attuning too greatly to specific groups as targets of certain kinds of disease and treatment has left out other presentations of the disease. This was the case in the early days of the HIV/AIDS epidemic, when the Centers for Disease Control (CDC) established a definition of AIDS based on opportunistic infections only applicable to male patients, effectively excluding women from meetings diagnostic

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[93] Brown, Wendy. "Suffering Rights as Paradoxes." *Constellations* 7.2 (2000) 208-229, 232. The emphasis is in the original.

[94] Williams, Patricia. *The Alchemy of Race and Rights.* Cambridge: Harvard University Press, 1992, 160.

[95] Brown, "Suffering Rights," 232-233. Again, emphasis is from Brown's text.

[96] For example in insurance plans that are not required to cover prescription birth control, yet at the same time there is no over-the-counter birth control option for women. The Affordable Care Act currently requires ACA compliant plans and government plans to cover birth control, but religious exemptions still obtain for religious employers.

criteria that would gain them access to treatment, even though women also contracted HIV/AIDS.[97]

Brown's analysis of how "rights secure our standing as individuals even as they obscure the treacherous ways in which that standing is achieved and regulated," and how "they must be specific and concrete in order to reveal and redress women's subordination, yet potentially entrench our subordination through that specificity"[98] complicates Young's appeal to turn attention toward social groups instead of merely take rights bearers to be sovereign, autonomous individuals. It does not negate the important role group recognition might play in redressing rights; it merely points to how such acknowledgement is a limited form of justice.

A problem for any rights to health care is the unequal distribution of needs among individuals as individuals, and as members of particularly identity groups (such as groups organized around citizenship status, age, medical condition, sex, etc.). Health and illness are not distributed equally, thus to meet health needs, responsibilities for health must be plastic enough to accommodate different types and level of need among and between rights holders, or by a single right holder across time or place, as a matter of equity and justice. Human rights approaches toggle between universal human experience, and needs of specific, often vulnerable, groups or individuals.

The Human in Human Rights

There is a prior question for human rights: what is the (or a) human? This is a question I cannot tackle in the scope of this project, though it is worth noting that debates about the nature of humanness, what it is to be human, metaphysical or otherwise, might influence what rights are recognized as intrinsic, specific, or extended to the human. Further, the inclusion or exclusion from humanity is a particular concern in the background of the following chapters in which I address cases of marginalization from moral and health care communities. Taxonomies of the human might rightly or wrongly look to features such as the capacity for suffering, or for rationality or morality.

Attempts at general classifications for humans tend to yield problematic results in individual cases, both for social justice, and for health care settings. For example, is an individual no longer human if they temporarily or permanently lose rational capacity? Is someone excluded from humanity if they are born with a severe intellectual disability and can never attain the capacity for

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[97] Shotwell, Alexis. "Women Don't Get AIDS, They Just Die From It': Memory, Classification, and the Campaign to Change the Definition of AIDS" in *Against Purity* by Alexis Shotwell. Minneapolis: University of Minnesota Press, 2016.

[98] Brown, "Suffering Rights," 238.

rationality or moral reasoning? Does being immune to certain forms of suffering – perhaps being desensitized to suffering through repeated exposure to it, or as a defense mechanism when experiencing trauma – compromise one's humanity? These are issues which health care faces, and which we might hope trigger the provision of care, not the exclusion from humanity.

The scope of humanness is also relevant to accounts of supposedly universal rights that nonetheless fail to include particular groups or subsets of humans. We might note this, for example, in Hume's critique of who was left out of the supposed "democratic" structure of ancient Athens (women, slaves, foreigners)[99] or in the rise in Enlightenment-era conceptions of universal rights that are nonetheless expressed as the Rights of Man (for example in the context of the French Revolution). In this latter case, mankind was not synonymous with humankind: "universal" rights were in fact only extended to white, male, citizens.[100]

That governments are the primary agent duty-bound to respond to human rights claims puts non-citizens in especially precarious circumstances. On the one hand, human rights look to universalize rights-holders to all humans. On the other hand, if states are bound to meet the demands of human rights, then citizens take priority over non-citizens and those unjustly excluded from citizenship.[101] Furthermore, claims for social justice in the name of human rights often point out the ways in which particular groups have been oppressed or treated as less than equally human.

From another standpoint, asking what or who is included in "the human" reveals another problematic aspect of the category. It masks important differences between groups who fall under the rubric of "human," but have particular identities and circumstances that lead to unique forms of injustice or oppression. Discourse regarding the "human" might conceal important ways in which humans differ.

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[99] Hume, David. "Of the Original Contract." *Essays – Moral, Political and Literary.* Indianapolis: Liberty Classics, 1987.

[100] Wendy Brown cites the Joan Wallach Scott book *Only Paradoxes to Offer* as a historical study of how nineteenth century French feminism was caught in a paradox in which the struggle for women's rights was responding to a particular language of the "rights of man." Brown, "Suffering Rights as Paradoxes."

[101] Benhabib says it is the "right of every human being 'to have rights,' that is, to be a **legal** person, entitled to unalienable rights, regardless of the status of their political membership." For Benhabib, being a human is to have rights, irrespective of recognition as a political citizen. However, paradoxically, inalienable and universal rights as humans are a legal right of recognition, conferred therefore by a legal institution such as a state. The category of human exists prior to state formation, but to have rights as humans is to have legal (state) recognition (Benhabib, 3).

Young critiques "modern political theory's tendency to reduce political subjects to a unity and to value commonness or sameness over specificity and difference,"[102] and Brown notes how being given rights according to a particular identity can be paradoxical. Arguably the category of the "human" does similar work of reducing individuals and groups to a sameness that fails to acknowledge their relevant differences. A universal category like the human risks becoming meaningless when it picks out nothing in particular.

While I am not taking a position on what it is to be human, if essential human qualities exist, or if humans are exceptional compared to other forms of life, human rights discourse privileges, and problematizes, humanness as a reason to have certain rights. In whatever way we construe the human, being human is not a sufficient condition for a normative theory of health care justice.[103]

Human Rights and Their (Potential) Justifications

There is a robust appeal to "human rights" and their supposed normative force with regards to moral imperatives, juridical processes and institutional structures across philosophical literature on social, political and global justice. This is no less true of the health justice literature. However, in appealing to such human rights, the meaning of these rights is not always made explicit, let alone justified. Claims for a normative concept of human rights entail political and civil rights and obligations, and the ever-present tension between human rights and civil and political rights appears to be an inconclusive puzzle for the relationship between this amalgam of rights and duties.

Appeals for the respect of human rights tends to take for granted that there are sufficient "conditions which establish or justify claims for their existence."[104] They might further assume that the contents of these rights are uncontroversial. There may be a reasonable grounding for human rights, but it is far from obvious what that would be, and it cannot be arrived at without controversy.

In the remainder of this chapter I argue that at best human rights have an explanatory function rather than a justificatory function: they explain aspirational objectives (which can be moral, legal, or both), but do not justify that their objectives are claim-rights. Human rights as

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[102] Young, *Justice and the Politics of Difference,* 3.
[103] I remain agnostic as to whether other forms of life (or even non-living entities) also have special rights, some or all of which may be shared with human rights. My objective is not to explode the concept of who has a right to care (for example, to extend the Affordable Care Act to domestic animals), though I do imagine that the implications of this project could have relevant implications for other forms of life.
[104] Becker, 17.

currently practiced might best be viewed as descriptive and perhaps prescriptive, in the sense of what a moral community aspires toward rather than what we can be commanded to do.

While at first glance this conclusion appears to strip human rights of their normative force, I think that this account offers useful opportunities for rethinking human rights, while avoiding some persistent pitfalls of common discourses that surround them. As a prescriptive project, I take this account of human rights, and particularly the concept of human rights to health care, to provide an invitation to develop a normative theory that can enact claim-rights due to identified beneficiaries, and accountable by specific addressees. I offer this account in chapters five and six.

Here I revisit and expand on potential accounts of human rights, that I started to touch on earlier in this chapter, along with relevant critique of human rights. In the next chapter I extend this analysis to the issue of human rights to health and health care in more details. Natural Law is one potential source of normative justification of human rights. According to Locke, "all men are born into a state of perfect freedom and equality as per natural law."[105] Yet feminist and race scholars challenge that equality and freedom are natural, revealing the ways in which they are socially constructed or prohibited. Nonetheless, an underlying principle of universal freedom and equally as sourced in a natural right to freedom and equality is often an intuition motivating human rights.[106]

According to Locke: "the fundamental duty of the law of nature is the preservation of mankind, or as much of it as possible," yet an "individual's **first** moral responsibility in this connection is to himself," prior to preserving mankind.[107] On this view of natural law, the individual is the primary agent of preservation, and fundamental rights are derived from individual needs. The move from the individual to the collective might occur insofar as each individual member of humankind shares in these same rights, and each is interested in self-preservation. Civil society enters as a tool to guarantee natural rights, and in this way human law is a supplement to natural law.

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[105] Locke, 269. His emphasis.

[106] Mary Wollstonecraft critiques this correlation between equality and natural law and on Lena Halldenius's reading of Wollstonecraft, "the distinction between natural and artificial is normative, not ontological" and "equality is a principle, not a fact." Halldenius, Lena. "Mary Wollstonecraft's Feminist Critique of Property: On Becoming a Thief from Principle." *Hypatia* 29.4 (Fall 2014): 942-957, 945. Kwame Anthony Appiah makes a similar point that equality is not "what morality demanded of us as individuals; it denotes a regulative ideal for political, not personal conduct. We go wrong when we conflate personal and political ideals," or assume they are the same. Appiah, Kwame Anthony. *The Ethics of Identity.* Princeton: Princeton University Press, 2007, 230.

[107] Waldron, 325. Emphasis in original.

Cecile Fabre holds a Lockean position that humans have certain natural and inalienable rights, and that they move from the state of nature to civil society to protect those rights. Fabre proposes a list of rights universally held rights to a minimally decent life, "irrespective of race, gender, sexual orientation, disability, and residence," that arise out of "human rights."[108] Fabre's "basic capabilities" include "life, body and health; bodily integrity; basic health and average longevity," in addition to emotional, intellectual, material and political means for flourishing.[109] These basic capabilities are intuitive and interpretive, but also aspirational. They are intuitive in the sense that life and health are likely uncontroversial goods. Yet health, longevity and flourishing are interpretive and context-driven. Furthermore, the latter goods (health, flourishing, longevity) are goals but not givens; in this way they are aspirational. Finally, these qualities cannot be objectively measured or standardized, let alone universally accessed.

Kwame Anthony Appiah contends that "we all" have human rights, or at least it is his belief that we do, but wants to ask the "practical question of whether we can expect everybody in the world (or at any rate almost everybody, once they give us a reasonable degree of attention) to come around to **agreeing** that we have those rights."[110] Despite acknowledging that human rights are "so weakly philosophically grounded," that they generate a "puzzle about what gives human rights instruments their power,"[111] Appiah offers no philosophical justification of his own for this power.

Appiah considers that human rights might be merely side constraints or negative rights,[112] because although "you could extend the claim of human rights beyond the realm of negative rights" to demand "that states ought affirmatively to guarantee certain basic needs... or by providing them themselves,"[113] he suggests states will fall short of these demands. To require that "a state has a duty to do what it cannot in fact do" is to "discredit the regime of human rights."[114] Because states cannot fulfill their duty, they must not have a duty to guarantee certain needs under a rubric of human rights; in other words, cannot implies ought not. Perhaps they should still strive to fulfill human rights, but there is not a duty to do so. Appiah does not generate an alternate response to who, other than states, if states will necessarily fail, must enforce human rights.

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[108] Fabre, Cecile. *Cosmopolitan War.* Oxford: Oxford University Press, 2012, 36.
[109] Ibid, 19.
[110] Appiah, 259.
[111] Ibid, 260.
[112] Ibid, 261.
[113] Ibid, 262.
[114] Ibid, 263.

In responding to charges against human rights, Michael Ignatieff offered a more moderate view of their aims. The critiques with which he contends include: that human rights are vague, unenforceable, and not grounded in philosophical principle; they conflict with cultural integrity, are a form of liberal imperialism, or a guise for global domination by super powers; and that they entail an esteem for the human that makes human rights resemble a form of religious creed.[115]

Brown characterized Ignatieff's position as the thought that "human rights activism is valuable not because it is founded in some transcendent truth, advances some ultimate principle, is a comprehensive politics, or is clean of the danger of political manipulation or compromise, but rather, simply because it is effective in limiting political violence and reducing misery."[116] In other words, human rights are not ontological, but normative. They respond to and represent the goal of limiting suffering, but are not a strict obligation to abolish it.

Extending Ignatieff's minimalist view of human rights, Brown adds that they are necessarily political, for they are aimed at producing justice, which is a political aim.[117] But this aim is also a form of political power. Human rights have the capacity to bring into being certain "subjects and political (or antipolitical) cultures" while they can "transform or erode" others.[118] Brown concludes that "rights are not just defenses against social and political power but are, as an aspect of governmentality, a crucial aspect of power's aperture."[119]

Brown's reading directly applies to a human right to health discourse: a human rights framework centers certain vulnerable groups, health issues, or medical or health conditions, focusing on these as targets for, indicators of, or conditions necessary to fostering a certain conception of basic health. Yet this conception of basic health and the selected initiatives of a human right to health campaign risks marginalizing other features of health or other conditions that contribute to one's health and access to health care.

Additionally, it raises questions regarding how we regard health diversity. Does a human right to health campaign require a basic definition of health that will marginalize individuals who do not subscribe to this normative definition (in particular those living with chronic disease or disabling

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[115] Brown, Wendy. "'The Most We Can Hope For. . .': Human Rights and the Politics of Fatalism." *The South Atlantic Quarterly* 103.2/3 (2004) 451-463, 451.

[116] Ibid., 452.

[117] Ibid., 453.

[118] Ibid.

[119] Ibid., 459.

conditions, who might reject the biomedical approach to health and illness)?[120] As discussed in the first chapter, I am on the side of health pluralism, and take health to be both a normative concept, and an aspirational one. But reasonable pluralism about health creates obstacles for the actionability of a coherent human right to health.

Ultimately, human rights face several paradoxes. They appear at once moral and political. They are empowering while they are a form of power. Natural law offers no more certain grounding than any other moral framework for deriving moral and political ideals, and should properly be seen as a normative framework with its own historical power and force. At best human rights themselves should be understood as normative moral and political objectives, that are socially and institutionally constructed, and ought not be derived from an attempt to define what is essentially or naturally "human."

Another paradox to human rights is what kind of rights these could be: claims, privileges, immunities, etc. As already discussed, claim-rights require corresponding obligations. A common refrain is that states are necessary for rights claims, in order to be accountable entities with corresponding duties. States may not be the only kind of institution that can enforce claims in practice, though it seems that some institutional accountability is necessary to generate the kind of responsibilities and accountability that human rights intend.

Benhabib offers a "discursive approach" that fills in some of the potential gaps in state failure to guarantee human rights, by highlighting individual accountability in moral communities. On her view, every person has a moral responsibility by being in a moral conversation with a partner to whom she must justify her actions.[121] Accordingly, the moral framework for responsibility is individual recognition of and communication between moral agents. Benhabib sources the right to have rights in legal and institutional recognition.

It is unclear in practice, however, how institutions could engage in moral dialogue with individuals as moral conversation partners when their rights are not recognized. What is the mechanism for individuals to hold institutions accountable when they fail to respect their rights claims, if individuals are also reliant on the institution to recognize them as having the moral standing to have rights in the first place? I will speak to this worry through the model of rights I offer in chapters five and six.

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[120] See Annemarie Mol on multiple ways of understanding the healthy or ill body. Mol, Annemarie. *The Body Multiple.* Durham: Duke University Press, 2002.

[121] Benhabib, 14.

Counter to the proposal that human rights are discursive norms, Brown challenges the notion that human rights provide a shared vocabulary for recognizing and discussing rights claims. She observes that human rights might instead "function precisely to limit or cancel such deliberation with transcendental moral claims, refer it to the courts, submit it to creeds of tolerance, or secure and escape from it into private lives."[122] A challenge then is how to see human rights as identifying areas of moral attention that can generate moral action.

One way to reconcile this thought is that even if there are certain inalienable rights, including perhaps the right to have rights, at best these rights are a privilege, but not a claim. For their inalienability means no one has a power to remove them, but there is insufficient grounding for the very existence of these rights let alone a mechanism for their enforcement, or a clear party with a correlative duty to bring them about.

Thomson seems to concede this point. She does not provide a justification for the moral grounding for human rights, but suggests that on any account of their grounding (like Appiah, assuming that they are grounded – or at least could be) human rights protect (as all rights do) against "removing, altering or failing to respect rights."[123] Unless these rights are waived, they are held by all individuals, and governments (or other individuals) cannot rescind them. But again, without a clear moral grounding for human rights, there will be discrepancies as to which rights individuals (or institutions) understand to be basic human rights. In certain cases, then, failing to respect rights would be failing to recognize a particular right as a human right.

Although I have emphasized the institutional role of being enforcers of and respondents to human rights, Benhabib's discursive ethics suggests a role for individuals, as members of moral communities, in responding to, reinforcing, and respecting human rights (even if the mechanics of that role remain opaque in practice). Insofar as individuals constitute and participate in institutions, they may be complicit in and accountable for the actions (or omissions) of institutions.

As evidenced by the title of this project, and noted in my introduction, complicity is central to the account of rights and rights to health care for which I argue in these pages. My own view draws on the work Christopher Kutz has done to establish a systematic framework for assessing

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[122] Wendy Brown critiques the supposed possibility that human rights provide a shared vocabulary for recognizing and discussing rights claims, noting that human rights might instead "function precisely to limit or cancel such deliberation with transcendental moral claims, refer it to the courts, submit it to creeds of tolerance, or secure and escape from it into private lives." Brown, "'The Most We Can Hope For…,'"458.

[123] Thomson, 292; citing Joel Feinberg.

complicity. Kutz offers an approach to assess individual responsibility within collective action. In his model, Kutz proposes a Complicity Principle, according to which individuals take responsibility for the harms caused by a group in which they participate, even if the individual did not directly contribute to said harms.[124]

I say much more about complicity, Kutz's account, main critiques of his account, and my own endorsement of his complicity framework, throughout chapters five and six. Complicity assessments are not without their shortcomings. When assessing complicity, questions arise regarding individual intention, group intention, epistemic position, choice, and power imbalances between individual groups members or between individuals and the group itself.

The view I offer will address some of these hurdles for complicity frameworks by focusing on intentional and complicit participation by individuals in a group, that render individuals complicit in the practices of the group itself, more than focusing on complicity for each particular action of the group. Moreover, I take Kutz to be primarily concerned with attributing responsibility for harms or wrongdoing. However, I think there is another, generative account of complicity as a tool for forward-looking responsibility that entails obligations to present and future action, obligations which arise by attributing responsibility (possibly in the form of blame) for prior wrongs and harms. I call this the positive side of complicity.

In chapters five and six I propose a model that engages moral agents in practices for recognizing each other's rights, and supporting processes for acknowledging and rectifying instance or prior failures of rights recognition, through a positive form of complicity. I argue this approach offers a powerful concept for understanding individual responsibility within (as well as a mechanism for the creation of) institutional frameworks. While this was not part of Kutz's project, it is in the spirit of his stance that our "moral, social, and legal institutions of accountability are themselves collective projects."[125] It offers a new avenue for how the individual is a participant in collective action alongside other individuals in moral, political or legal institutions.

Up to know I have considered an account of rights, noting that in the strictest sense, claim-rights entail corresponding duties. I invoked several, primarily feminist, critiques of rights relevant to rights discourse as well as human rights discourse. Then I surveyed several approaches to human rights, suggesting that they do not sufficiently ground a concept of human rights, given the nature of

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[124] Kutz, Christopher. *Complicity: Ethics and Law for a Collective Age.* Cambridge: Cambridge University Press, 2007, 122.

[125] Ibid., 255.

right themselves (setting aside the problem of what it is to be human). In the next chapter I turn to the literature on health and health care as a human right.

As I noted at the outset of this chapter, there is a theoretical problem within the health as a human right literature: it largely collapses health and health care into one and the same right, or uses the terms interchangeably. I have already argued in the first chapter that health and health care ought to remain distinct concepts, and that health is an ideal or aspiration while health care is a practice arising out of relations of care. I have also argued in the previous chapter that health care ought to be understood much more expansively than mere medical care. This point responds to thus the worries of those who appeal to health because they understand it to be a more inclusive concept, in contrast to a minimal package of mere medical care. On my view, health care can and ought to be more expansive, and is better positioned than health to correlate to clear rights and responsibilities.

However, in the next chapter I follow the literature in discussing a human right to health, in part because I ultimately argue that iterations of both a human right to health and a human right to health care fall short of doing the normative work they intend. Building on the analysis of rights and property rights in this chapter, I conclude the next chapter by evaluating theories of self-ownership as an alternate route into rights to health care. Although I argue that both a human right and a self-ownership right to health care approach are theoretically insufficient, I take them to invite conceptual and activist engagement toward a successful framework for a claim-right to health care. I offer my own such framework in the final chapters of this project.

IV

Health Care Houses

In this chapter I consider two ways into rights to health care: human rights and self-ownership rights. I argue that though they are very different approaches they nonetheless face a similar problem. Human rights approaches focus on broad, universal rights with substantial state involvement and responsibility. Self-ownership approaches focus on narrow individual rights within a libertarian tradition and a minimal state. Yet in practice both end up treating rights as things that the rights-holder owns or possesses. I call this a "house" model of rights, in which rights are goods owned by the rights-holder, similar to how a house can be bought, sold, transferred, and possessed. The notion of owning rights according to a property model is insufficient (and is rooted in historical injustices of property-ownership discussed in the previous chapter). In the following chapters I contrast this "house" model with my "home" model of rights. In my theory of an "ethical home," conceptual homes are source of rights, and this approach generates different, and I argue, more actionable, accountabilities and responsibilities. This includes actionability and accountability for rights to and practices of health care.

In the previous chapter I broadly considered rights, and indicated that I am interested in claim rights to health care. I argued that human rights are not claim rights. My view is that human rights are aspirational rather than binding.[1] In the first chapter I argued for a distinction between health and health care. Health is an aspirational and descriptive concept; and we can (and should) be value pluralists about health. Health care is a normative concept, according to which we can (and should) establish accountable practices compatible with health pluralism. Building on these two premises, in this chapter I propose that a human rights framework is a less than useful tool for health care justice.

Human rights largely set aspirational goals for health, without filling in the necessary practice of care. Furthermore, human rights problematically attribute responsibility to fulfil the rights they set out to protect, at least with regards to health care, by making states the primary responsible agents.

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[1] Joel Feinberg also has a version of this view, in which human rights express "prima facie" claims "worthy of sympathy and serious consideration" even if they are not "**valid** claims" that act "as grounds of any other people's duties." Emphasis belongs to Feinberg's text. Feinberg, Joel. "The Nature and Value of Rights." *The Journal of Value Inquiry* 4.4 (1970): 243-260, 254-255. Charles Beitz defends that abstract rights set goals in Beitz, Charles R. *The Idea of Human Rights*. Oxford University Press, 2011.

Although human rights putatively apply to all who are categorized as "human," in practice they are primarily extended to those who are categorized as "citizen" by a state responsible for the rights of its citizens.

Ultimately, I suggest that a human rights approach ends up treating rights as things that are possessed by individuals because the status of citizenship functions similar to a good that is owned, rather than merely a status that is recognized. States in particular have a responsibility to fulfil the corresponding duties entailed by rights – but this is primarily for those who "possess" recognized citizenship within a state. I further argue that this does not meet a just account of health care. I engage an example related to pregnancy and prenatal care for undocumented migrants in a US context to illustrate shortcomings for a human rights approach to health care, and how it fails to provide undocumented migrant patients with just health care.

Then I turn to the concept of rights originating through self-ownership. Self-ownership is considered in the literature to be a central thesis for libertarian arguments for rights within a minimal state. I argue that swinging the pendulum away from a broad category like humanity toward the discreet unit of the individual is no more successful in providing a foundational justification for rights to health care. Through another example related to pregnancy and maternal-fetal health, I assess several problematic implications for a self-ownership framework when it comes to a right to health care in practice.

I diagnose both the human rights framework and self-ownership framework as upholding a problematic conception of rights that I term a "house" model of rights. By this I mean that they defer to concepts of ownership and property rights. As I argue, human rights in practice extend primarily to those who possess citizenship, and self-ownership rights extend to those who possess their bodies. My focus instead is to reframe rights away from possession and towards relationships that we form in community, to others, and with ourselves, that construct rights frameworks in which individuals are both rights-holders and rights-enablers, with obligations to fulfil duties toward other individuals.

In contrast with a spurious "house" model of rights, I call this relational view of rights a "home" model for reasons I elaborate in the final two chapters. Unlike houses, which are uniquely owned and controlled, homes arise out intersubjective and collaborative processes of home-making. In the following chapters I present my ethical home model for grounding rights to and responsibilities for health care in something between a radically universal or radically individual source. I argue my approach overcomes the shortcomings of a house model of rights that we see with both human rights and self-ownership rights approaches in this chapter.

Human Rights to Health Care

In this section I analyze several core international documents that comprise a putative human right to health, and key arguments for and against a human right to health or to health care. I show why a right to health care is more successful than a right to health, based on arguments in chapter one regarding the distinction between health and health care. Yet a human right to health care still yields insufficient normative force. My project is not to downgrade human rights such that health care is an aspiration instead of a right. My objective is to normatively ground rights to health care in something other than human rights such that they can become claim-rights, with clear correlative duties held by identifiable groups and their members.

I look more closely at three main sources of human rights to health or health care: The Universal Declaration of Human Rights (UDHR) Article 25; the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12; and General Comment 14, which is a companion to the ICESCR that addresses the "highest attainable standard of health." Specifically, I analyze these documents in light of my claims regarding rights in the previous chapter, and in conversation with representative literature on the human right to health or health care.

Supporters of a human right to health are led by Jonathan Wolff, though versions of the argument in favor of a human right to health or health care are also captured by Allen Buchanan and Nicole Hassoun, among others. Gopal Sreenivasan articulates a version of what he describes as a skeptical argument, while other related flavors of skepticism are voiced by Onora O'Neill and, arguably, Norman Daniels.[2] Notably, the central debate is not the intended outcome or objective of a human right to health or health care view, but largely the mechanics and justification for the view.

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[2] This interpretation of Daniels is forwarded by Martin Gunderson, who sees Daniels's view on health care justice as context-dependent and therefore counter to the possibility for a universal right or standard (see Gunderson, Martin. "Does the Human Right to Health Lack Content?" *Social Philosophy Today* 27 (2011): 49-62 and Hassoun, Nicole. "The Human Right to Health."). Allen Buchanan engages in a different debate with Daniels regarding a right to minimal health care that is not primarily grounded in human rights discourse, but which I will touch on later in this chapter.

In 1948 the Universal Declaration on Human Rights (UDHR) included Article 25, specifically addressing the category of health.[3] According to Article 25:

> 1. Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. 2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Importantly, this document is a declaration, and therefore non-binding, unlike a convention, treaty or covenant, which comprise international law.[4] Not until the 1976 International Covenant on Economic, Social and Cultural Rights (ICESR) is a commitment to health and health care ratified as international law (by most, though not all, nation-states). Article 12 of the ICESR endorses a robust commitment to health saying that "1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." It goes on to specify:

> 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right." These specific steps "shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child; (b) The improvement of all aspects of environmental and industrial hygiene; (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.[5]

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[3] United Nations Office of the High Commissioner for Human Rights. "Universal Declaration on Human Rights," December 10, 1948. Accessed November 27, 2018. https://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf

[4] According to Larry May and Shannon Fyfe, "international law is on strongest grounds when it is based on multilateral treaties that states ratify requiring the parties to the treaty to restrict themselves in the future. Treaties are often rightly said to be a form of contract" (29). May, Larry and Shannon Fyfe. *International Criminal Tribunals: A Normative Defense.* Cambridge: Cambridge University Press, 2017.

[5] United Nations Office of the High Commissioner for Human Rights. "International Covenant on Economic, Social and Cultural Rights," Article 12, January 3, 1976. Accessed November 27, 2018. https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx

196 states are parties to the ICESR, while four states, including the United States have signed, but not ratified, the covenant, and 24 states have taken no action on the matter.[6] General Comment 14 further details the definition of health developed by the Committee on Economic, Social and Cultural Rights. According to General Comment 14, "health is a fundamental human right indispensable for the exercise of other human rights"[7] and "health is more expansive than the provision of health care."[8] Not all states view General Comments as legally binding,[9] though the document indicates three kinds of state obligation, according to which states are require to respect, protect, and fulfill a right to health.[10]

Article 25 of the Universal Declaration on Human Rights and Article 12 of the International Covenant on Economic, Social and Cultural Rights, along with its companion General Comment 14, invite further theoretical and practical consideration. In the previous chapter I argued against human rights as a normative grounding for claim-rights. However, these documents advocating for health care access in the name of human rights present important ambitions for the scope and content of health care, even if the foundation for doing so is, according to my analysis, unfounded.

The documents express widely held moral intuitions. It is possible these intuitions track onto a theoretical foundation, and furthermore that they could entail concrete responsibilities held by delineated individuals and groups. As it stands, such a theoretical foundation and entailment of concrete responsibilities is lacking. What could it look like to more fully address, in a binding way, the nature of health and well-being the UDHR describes? Although 196 states have signed on to the ICESR, committing to create "conditions which would assure to all medical service and medical attention in the event of sickness," we know in practice that many of these states cannot or will not work toward this step. Part of the problem, I argue, is with the operative notion of rights underpinning human rights discourse and health rights discourse.

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[6] United Nations Office of the High Commissioner of Human Rights. "Status of Ratification Interactive Dashboard" Accessed November 27, 2018 http://indicators.ohchr.org/

[7] United Nations Committee on Economic, Social and Cultural Rights. "General Comment No. 14, The right to the highest attainable standard of health." August 11, 2000. Geneva: United Nations, 2000. Accessed December 21, 2018 https://digitallibrary.un.org/record/425041

[8] Gostin, Lawrence O. "The Human Right to Health: A Right to the 'Highest Attainable Standard of Health.'" *The Hastings Center Report* 31.2 (2001): 29-30, 29.

[9] Wolff, Jonathan. *The Human Right to Health,* New York: Norton & Company, 2012, 31. The United States is one state that does not regard General Comment 14 as a legally binding document.

[10] Gostin, 30.

Jonathan Wolff observes a frequent "slip between rights talk and human rights talk without marking the difference."[11] He clarifies that on a legal view "human rights could be thought of as simply those rights declared to be human rights in international treaties and declarations," but adds that the intent behind the UDHR suggests "human rights have a double role" with a moral function to express "minimum moral obligations owed to human being simply by virtue of their existence as human beings" and an institutional function to "generate a mechanism of accountability beyond the nation-state."[12] As such, the UDHR sets out basic moral commitments rather than claim-rights.

The United Nations characterizes the UDHR as setting moral guidance for the development and ratification of subsequent, binding, international law.[13] The normative source of the moral grounding is not articulated. Wolff suggests that the UDHR is an example of a Rawlsian overlapping consensus, in which different reasons are given for arriving at a shared conclusion, or set of conclusions. The shared conclusion takes the form of the list of human rights enumerated by the UDHR,[14] and then codified into international law in 1976 with the ICESCR.[15] Yet the tension between moral right, moral aspiration, and binding law is among the conceptual stumbling blocks for a human right to some form of health or health care.

Adding to this tension is the content and form of General Comment 14, on the "highest attainable standard of health." General Comment 14 was produced by the Committee on Economic, Social and Cultural Rights to clarify the definitions and mechanisms set forth in Article 12 of the ICESCR that establish the legal human right to health. General Comment 14 articulates that "the right to health is not to be understood as a right to be healthy."[16] Yet a right to health is more expansive than a right to what is construed as mere health care (which we should probably read as mere medical care).

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[11] Wolff, *The Human Right to Health,* 16.

[12] Ibid.

[13] United Nations. "Human Rights Law." Accessed December 23, 2018 http://www.un.org/en/sections/universal-declaration/human-rights-law/index.html.

[14] Wolff, *The Human Right to Health*, 20.

[15] Wolff, Jonathan. "The Demands of the Human Right to Health." *Aristotelian Society Supplementary Volume*, 86.1 (2012): 217-237, 217.

[16] United Nations Committee on Economic, Social and Cultural Rights. "General Comment No. 14" Article 8. Allen Buchanan deems a right to be healthy as implausible because this is "not within the domain of social control." Buchanan, Allen E. "The Right to a Decent Minimum of Health Care." *Philosophy & Public Affairs* 13.1 (1984): 55-78, 55. I have also argued against both a right to health and a right to be healthy in chapter one, favoring instead a right to health care according to an expanded account of the concept of health care.

General Comment 14, the ICESCR, and the UDHR wrongly, in my view, consider health care as identical to medical care. As already argued, I am in favor of an expanded view of health care that is not mere medical care, but instead includes a comprehensive provision of many of the social, political, and economic means necessary to support good health care. General Comment 14 does include other necessary basic features such as sanitation, clean water, adequate food and nutrition, and shelter in an overall picture of health.[17] These could be better captured as features of good health care, rather than simply parallel to health care.

Furthermore, General Comment 14 specifies that it is the duty of states to progressively realize a human right to health for its citizens through the availability, accessibility, acceptability, and quality of health care it provides .[18] It qualifies said obligation by noting that resource distribution, biological, and socio-economic factors all weigh on the "highest attainable standard of health" that a state can be reasonably obligated to ensure and protect.[19]

Critics of human rights documents argue that the objectives they contain are unrealistic given the reality of resource distribution and structural and economic disparities between states.[20] Moreover, it is unclear how states are held accountable by human rights pronouncements.[21] There is an outstanding worry that the values and expectations contained within supposedly universal human rights documents are in fact expressing western values to the exclusion of other cultural views.[22]

While a human right to health may not express specifically western values, I argued in the first chapter that the concept of health appeals to normative ideals regarding what is valuable about health, and these ideal will be context-specific. I further argued in favor of value pluralism about health; there is not, and should not be, a single monolithic view or conception of health. Therefore, I do endorse the idea that human rights documents might not be able to accommodate value-

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[17] All of these are enumerated as relevant to health in the United Nations Committee on Economic, Social and Cultural Rights "General Comment No. 14" Article 4.

[18] Ibid., Article 33 names the obligations to "respect, protect and fulfill" a right to health and Articles 30-31 articulate the principles of progressive realization.

[19] Ibid., Articles 9-12.

[20] Daniels, Norman. "Fair Equality of Opportunity and Decent Minimums: A Reply to Buchanan." *Philosophy & Public Affairs* 14.1 (1985): 106-110, 107. Daniels suggests that normal opportunity range is location-specific and contingent upon a state's "stage of historical development, its level of material wealth and technological development" and culturally unique features (107). Though this might capture a teleological view of history that is no longer fashionable.

[21] Wolff, *The Human Right to Health,* 17.

[22] Ibid., 21.

pluralism about health and the different normative conceptions of health expressed across different cultures, communities, times, or even among diverse individuals.

Following the drafting of the UDHR, the American Anthropological Association raised concerns that the declaration does not reflect how individuals and their values are shaped by their cultural context.[23] The American Anthropology Association critique invites reflection regarding how we could conceive of rights and membership differently, that is to say, in a way that is localized to, reflective of, and produced within, a specific community of membership. I will take up this invitation for further reflection in the next chapters when offering my model of a moral community as an ethical home. My account will accommodate value-pluralism about health by focusing on establishing normative practices for health care, rather than for health, a distinction that some have argued is perhaps irrelevant for human rights frameworks.

For example, Hassoun claims that many analyses of human rights frameworks focus on the right to health care, but that rights to health "will almost certainly ground derivative rights to care, and some of the proposed bases for a human right to health care may provide alternative grounds for a human right to health."[24] Based on this reasoning, Hassoun treats human rights to health and health care as practically interchangeable.

Yet, as I continue to emphasize, health and health care are distinct concepts. They have different meanings and scopes, and on my conceptualization of each, only health care can ground claim rights. I therefore think it is an error to establish a human right to health. It is also incorrect to promote a human right to health in contrasts with a narrow definition of health care that conceives of health care as merely medical care.

My expanded notion of health care would in fact more adeptly respond to the commitments articulated in General Comment 14, in which Article 1 claims that health is a precondition for the achievement of other rights,[25] and Article 2 clarifies that the UDHR sets out a "right to a standard of living adequate for the health" of individuals and their[26] families and recognizes "social services" and "food, clothing, housing, and medical care" as necessary in order to meet the demands of a right to a

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[23] Ibid., 22.

[24] Hassoun, 277.

[25] United Nations Committee on Economic, Social and Cultural Rights. "General Comment No. 14" Article 1.

[26] The document itself defers to the masculine pronouns that presume the individual is male and responsible for "his family."

certain standard of living.[27] Article 3 of General Comment 14 indicates that "the right to health is closely related to and dependent upon the realization of other human rights" which are "integral components of the right to health."[28] Good health care corresponds to a bundle of features that are mutually reflexive, and support one another.

Yet even were we to exchange all instances of a "right to health" with a "right to health care," and this right to health care were to conform with my expanded definition of health care, I still find human rights to be an insufficient framework for grounding and protecting this right. That health (or better: health care) and other rights might work best in concert, or even stronger, that they cannot be fully realized without the other, renders them of great importance to each other. But it does not support why any of them are a right in the first place.

There are additional background values and commitments necessary to explain and do the justificatory work of each, or all, of these rights as rights. Human rights declarations are informed by natural law beliefs, but not dispositive for the validity of those beliefs.[29] The very possibility of natural and inalienable rights is a matter of debate, not fact. For example, Locke argued for natural and inalienable rights, while Bentham said the concept of "natural rights is simple nonsense" and "rights are the child of the law."[30]

What happens if we look past the problem of grounding natural law and grounding human rights more generally? To some extent this is what many of those who subscribe to a human right to health view do: they accept the problematic foundational aspects of human rights as a bullet to bite in order to pursue the "practice" of human rights, as Wolff characterizes it. Wolff adopts a view of human rights from Joseph Raz. According to Raz "human rights need not be universal or foundational."[31] Human rights as a practice overcome, according to Raz, standard approaches to human rights which fail when they place too much emphasis on moral foundations of human rights, or when they connect human rights too closely to human personhood.[32]

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[27] Ibid., Article 2.
[28] Ibid, Article 3.
[29] A point similar to the observation from Thomson referenced in the previous chapter that merely because natural law systems would be efficient does not mean that they are true. See Chapter 3, page 100.
[30] As cited in Wolff, *The Human Right to Health,* 19.
[31] Raz, Joseph. "Human Rights Without Foundation" in *The Philosophy of International Law* edited by Samantha Besson and John Tasioulas. New York: Oxford University Press, 2010, 392.
[32] Ibid., 382-383.

Instead, Raz follows Rawls by taking "human rights to be rights which set limits to the sovereignty of states" such that in cases of "actual or anticipated" violation of human rights, interference from outside states (that is normally impermissible) becomes permissible.[33] Human rights construed in this way are a mechanism for disabling protections of state sovereignty, and triggering external accountability of states toward other states or international bodies like the United Nations.

On such a view, human rights do clear work: they remove prohibitions against external interference in order to hold states accountable (to other states and to international bodies). But we might still worry about what work they do internal to the state when there are disparities in the protection of rights, and whether this truly triggers intervention by outside actors. My greatest concern is regarding those who are members of a community in practice, but are not institutionally recognized members of the state. Further, if abstract human rights function in part by allowing states to attune them to their unique context,[34] then will states recognize interference from other states, who perceive them to be failing to meet their human rights obligations, as justified?

Perhaps if states were cognizant of their own apparent human rights failings, and these failings justify external interference, they may be more likely to internally address these failings. Or, states could actively seek outside assistance in addressing their human rights obligations such that the situation would not escalate to a scenario in which external actors impede on state sovereignty by imposing human rights interventions on the state and its occupants. But if they neither recognize nor acknowledge their own human rights failings, what is the practicable next step besides intervention by an external actor? And what form of intervention should this take? Need it be aggressive? We have enough recent examples of so-called humanitarian intervention by state actors in other states to wonder if the humanitarian gains can at all outweigh the humanitarian set-backs.

Some argue for an instrumental value to a human rights approach to health. The value of health becomes justification for the practice of human rights, rather than the practice as justified by intrinsic foundational values. So human rights can help set guidelines for appropriate health-related rationing; can promote the values of solidarity or equality; or give reasons for striving toward better

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[33] Ibid., 386.
[34] See Gunderson, "Does the Human Right to Health Lack Content?"

health policy and outcomes.[35] But that "human rights indicators are one promising way of encouraging positive change"[36] does not prove a human right to health is philosophically sound. It merely suggests that it is practically and politically useful. Sreenivasan situates his skeptical account of a human right to health within a moral rights framework, and suggests that although health is morally important, this moral value does not generate a claim-right to health.[37] Following my arguments in the first chapter, I agree with Sreenivasan that there is not a claim right to health (though I maintain that there should be a claim-right to health care).

Part of the problem for the debate within the human right to health literature is that it moves between those who seek to morally ground the very existence of human rights, and by extension a human right to health, on one side, and those who are content to overlook the unstable theoretical foundations for human rights to reap the practical rewards related to health outcomes. Once we recognize these differences in kind between the arguments, however, I think it is possible to both practically and philosophically ground a claim-right to health care, but not to health, and not via human rights frameworks.

As I discussed in the previous chapter, human rights encounter justificatory problems, relying too heavily on faulty natural law suppositions. Human rights also encounter problems of scope. To have human rights, we need to identify who counts as human, in order to know to whom human rights apply. Who and what counts as human are not always straightforward questions. By engaging an example of a human rights response to health care for an undocumented pregnant person, I will now show how the reliance on a construct of the "human" can have dangerous, and politically-motivated, effects on health care access, especially when human rights are intertwined with civil rights, as I argue they often are.

I show through in this example that human rights are purportedly universal, yet in practice they require state recognition since states are the main agents with responsibilities to fulfill and protect human rights. This means that in practice human rights become civil rights, and they accrue to those who have recognized citizenship or otherwise lawful presence within a state. Yet citizenship and lawful presence within a state such as the United States are granted through practices akin to property rights, on my view, which are themselves historically unjust practices. I elucidate these

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[35] Hassoun, 281. See also: Semplici, Stefano. "The Importance of 'Social Responsibility' in the Promotion of Health." *Medicine, Health Care and Philosophy* 14.4 (November 2011): 355–363; Sreenivasan, "Human Right to Health?" and Wolff, "The Demands of the Human Right to Health."

[36] Hassoun, 281.

[37] Sreenivasan, 241.

claims by analyzing two versions of a hypothetical case of health care in a US context. I revisit many of the same themes contained in this case, though from a very different perspective, when I analyze the concept of rights originating from self-ownership in the final section of this chapter.

The Case of an Undocumented Immigrant Patient in the United States

An undocumented woman living in the United States is 34 weeks pregnant and has not previously presented for any prenatal visits because she is uninsured, and is worried about interacting with health care providers due to her immigration status. She has family in the US, who are a mix of documented and undocumented immigrants; several of her nieces and nephews are US citizens. The woman has been having worsening headaches and abdominal pain. When she experiences a sudden but temporary loss of vision her partner takes her to the emergency room at the local hospital. Let's imagine two different pathways for her diagnosis:

Scenario A: The hospital diagnoses the woman with preeclampsia, and because the fetus is viable, recommends immediate delivery via emergency cesarean section due to risk to both the woman and the fetus if the pregnancy continues.

Scenario B: The hospital was initially concerned that the woman was presenting with preeclampsia or another pregnancy-related condition. However, following an initial workup, her pregnancy appears healthy. Only after further testing do doctors identify that the woman has a brain tumor that may require surgery, and will certainly require treatment with the oncology team on an out-patient basis.

In Scenario A the woman experiences a scary, and life threatening, complication with her pregnancy. It is one that would have possibly been avoided had she sought medical treatment sooner, or it could have been managed in ways that would not have resulted in emergency circumstances. However, by presenting to the emergency room for care means that her medical expenses will be covered by emergency Medicaid.[38] It also means that the costs to the Medicaid

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[38] Under US Law, the Emergency Medical Treatment and Active Labor Act (EMTALA) which has been in force since 1986, a hospital would be obligated to treat a patient with emergency needs or in active labor no matter what department of a hospital or health facility she presents to, so this does not only apply to patients in the emergency room, but this is the most common site of where patients are treated for emergency needs

system are arguably much higher than if she had been receiving Medicaid-funded prenatal and preventative care.[39] Colleen Lee argues that there are human rights reasons for undocumented people to have access to health care in the US, but there are also practical rather reasons to extend prenatal care to undocumented persons: doing so would lead to better health and economic policies and outcomes.[40] Economic policy aside, looking only at health outcomes, people who do not receive prenatal care are "three times more likely to give birth to babies with low birth weight, and infant mortality is five times greater."[41]

Even though providing prenatal care to undocumented pregnant patients extends health care to non-citizens who do not have legal standing in the US, it also protects the interests the US has in its own citizens. If the US is concerned with the health of its citizens, then providing prenatal care to people pregnant with future US citizens looks to be in the nation's best interest given the greatly improved health outcomes. This is why Scenario B is a particularly interesting, and fraught, case.

In Scenario B, the pregnant person has a health care need. But this need pertains to her own health, and is not one related to her pregnancy, nor the fetus. And while her health care need is both urgent and serious, it is not, necessarily, an "emergency." It will, instead, require longer-term care on an out-patient basis. One option available in both Scenarios A and B is to enroll the pregnant patient in Medicaid through the Children's Health Insurance Program (CHIP). CHIP is a state-funded program for US citizen children who meet age requirements, and whose families meet income requirements. US citizen children of undocumented parents are as equally eligible as any other US citizen child if they meet these requirements.[42]

In 2002 the definition of a child as per the legislation guiding CHIP changed to include fetuses; this has allowed states to elect to use "CHIP's unborn child option to provide prenatal care to undocumented immigrants" who will deliver US citizen children once they are born on US territory.[43] For both patients, in Scenarios A and B, the coverage to the pregnant person will conclude 30 days after delivery. This is an unfortunate but manageable, assuming a smooth post-

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regardless of their ability to pay for their care. Hall, Mark, Mary Anne Bobinski and David Orentlicher, editors. *Health Care Law and Ethics*. New York: Wolters Luwer Law & Business, 2013, 125.

[39] Lee, Casey Colleen. "Unjust Barriers: Prenatal Care and Undocumented Immigrants." *The Journal of Contemporary Health Law and Policy* 31 (2015): 96-119.

[40] Ibid., 98-99.

[41] Ibid., 98.

[42] Ibid., 100.

[43] Ibid.

partum recovery for the pregnant person, feature of the legislation in Scenario A. For the patient in Scenario B, this limited coverage will not accommodate all of her necessary medical treatment.

Extending health insurance during the prenatal and immediately postnatal period to persons who will deliver US citizen children by enrolling them on CHIP protects the government's interest in its citizen population, however, there are several other arguments in favor of supporting prenatal care for undocumented immigrants that are not only applicable to prenatal health care and interest in future US citizens. As already noted, there are significant practical arguments including: it is more financially prudent to provide prenatal care than address emergency care that arises due to the absence of prior medical access;[44] providing such care does not appear to impact the volume of illegal immigration[45]; and undocumented persons often pay taxes and therefore are contributing to the state-sponsored systems that they would be using.[46]

Preventative medical care is generally effective at improving health outcomes and lowering emergency health costs across the health landscape, and not only regarding prenatal care.[47] Undocumented immigrants paying into taxes are not limited to pregnant or potentially pregnant people, but include a wide range of people who could be, but usually are not, accessing a health care system. At least one moral argument in favor of undocumented access to health care notes that such non-citizens are not only members of the economy but also members of families and social networks (among citizens and noncitizens) with ties to the US.[48] Both these practical and moral arguments regarding undocumented immigrant participation in the US social tapestry feature in the view of membership and ethical homes I articulate in the next two chapters.

In our Scenario B, therefore, let's assume the patient presents to a hospital in a US state that extends to unborn US citizens the right to access CHIP, and covers health insurance for the pregnant person carrying the pregnancy. This means that our patient in Scenario B has health insurance from the time she presents to the hospital at 34 weeks pregnant, until 30 days postpartum, when the child will need to be insured separately from its mother. At this juncture the child is still

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[44] Ibid., 107.

[45] Ibid., 108.

[46] Ibid., 110

[47] This point is different from the observations made earlier that access to health care has comparatively lower impact on health outcomes than other social determinants of health. Access to preventative medicine will still impact overall outcomes relative to lack of access to preventative medicine for conditions that can be prevented or managed better through early detection.

[48] Lee, 112.

eligible for CHIP, but the mother's enrollment on health insurance will discontinue. Yet it is precisely during this time post-delivery that the mother will need to access necessary medical treatment for her brain tumor in order to care for her own health, and to have a shot at remaining alive and healthy to care for her US citizen baby.

Scenario B shows that in the US, the country with the highest spending on health care in the world,[49] there is not an available mechanism to channel health care to a woman living on US territory, who is potentially gravely ill, short of while she is pregnant with a future US citizen. Can a human right to health or health care help?

Again, because the human rights literature focuses mainly on a human right to health, though in other instances treats health and health care as interchangeable, I continue to consider both the notion of a human right to health and a human right to health care in this section. Though I largely defer to the more common right to health language. Mindful of my arguments from chapter one against a right to health and in favor of a right to health care, I show how in practice this distinction plays out in the cases I have presented.[50]

If human rights are legal rights, and provide a justification for rejecting a state's sovereignty when not respected, we might wonder: if a human right to health ought to grant our undocumented patient an unalienable right to health, and to the health care necessary to protect it, then if the US context in which she lives fails to protect and fulfill this right, will other states hold the US accountable?

The US might reply that the patient ought to return to her country of origin, where she would be recognized by the state, and can therefore access state benefits, including to health care. However, it is not guaranteed that her origin country recognizes her citizenship either, or that it is capable of meeting her human right to health. She may have fled that country for its very failures to recognize her as a full citizen, or to respect and protect her human rights, to health or otherwise.

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[49] Papanicolas, Irene, et. al. "Health Care Spending in the United States and Other High-Income Countries." *JAMA*. 319.10 (2018):1024–1039. The US spent almost twice as much as other high-income countries in 2016, yet performed less well on many population health metrics. Notably, the higher spending could be attributed primarily to the cost schemes of labor, pharmaceuticals and medical devices and not to social health spending or higher health care utilization.

[50] Furthermore, when I talk about health care throughout this chapter, I am primarily talking about traditional accounts of health care that are currently in practice, which equate health care with access to a medical system. This is not the vision of health care I think ought to be in place, as I argued in chapter two, but it is the one we generally have in place when analyzing current opportunities and failures of rights to health care approaches.

Senator John McCain described the US Affordable Care Act (ACA) as "one of the privileges of citizenship." He went on to say: "That's just what it is. I don't know why we would want to provide Obamacare to someone who is not a citizen of this country."[51] Not being a citizen (and perhaps not even being a legal immigrant on McCain's view) is reason to exclude someone from state-supported health care, which effectively means many undocumented persons in the US are uninsured. The only routes to health insurance for undocumented individuals would be through employment-sponsored health insurance (though they also lack legal documentation to work for an employer who could sponsor their health care), or self-paying for insurance at full price, since they are not eligible for state-sponsored insurance or state-supported subsidies under the ACA.[52]

While US federal policy largely excludes undocumented immigrants from Medicaid or ACA programs, local responses to health care can vary. It is at the discretion of state or city governments to enact policy in their own jurisdictions to extend certain kinds of coverage or protections to undocumented immigrants. Yet even these localized policy protections primarily extend to those with some official status (such as Deferred Action for Childhood Arrivals, or DACA) or they do not cover health care as much as protect against being reported to immigration agencies for people who present to health care (in the case of sanctuary cities, or hospitals for that matter; the latter do not coordinate with or report to US immigration officials about their patients as matters of practice and ethics).

Despite such legal protections for individuals presenting to health care, the costs are still largely covered in ad hoc ways, and through emergency mechanisms like our patient in Scenario A. This means that people both delay or refuse early treatment until a problem becomes urgent, and that the cost of emergency treatment tends to be much higher than the cost of routine care or preventative care. And this does nothing to address the other socio-economic factors that influence

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[51] Lee, 111.

[52] Henry J. Kaiser Family Foundation. 2017. "Health Coverage of Immigrants." December 17, 2017. Accessed December 30, 2018 at https://www.kff.org/disparities-policy/fact-sheet/health-coverage-of-immigrants/ 83% of undocumented non-elderly immigrant households in the US have at least one full-time employed worker (which is the same as for citizen and legal immigrant households) yet undocumented immigrants are uninsured at a rate of 40% compared to only 10% of non-elderly adult US citizens and 18% of legal immigrant non-elderly adults in the US. If a person is undocumented then they are not likely to have access to the kind of job that offer employer sponsored health insurance as this would likely require a legal right to work. My concern is not with the few who can travel to a country such as the US without proper documentation in order to pay out of pocket for medical treatment, though this does occur. It speaks to another way in which purchasing rights to care is unjust that I do not have the space to unpack in these pages.

health and care, which, as I argued in chapter two, ought to be part of an expanded definition of health care.

What I think these imagined Scenarios A and B, and the possible responses available to them, show is that in practice purported universal human rights are in fact enacted through citizenship and civil rights. It is not that one has a right to health care because she is human and her humanity entails rights to basic standards of health or well-being (according to whatever model of either one wants to adopt[53]). Instead, these presumed rights to health and health care follow from being a member of a state with civil rights conferred through citizenship (or perhaps civil rights conferred through legal immigration even if not full citizenship).

The absence of federal support to undocumented patients reveals a shortcoming with a human rights framework: it is supposed to obligate states to protect and fulfill duties of health care, yet in practice health care rights extend only to a state's own citizens (or legal non-citizens), at least on the example of the United States. Certainly, the spirit of a human rights approach would suggest that a state's obligations extend to all those falling within its jurisdiction (and perhaps also to those outside of it, in the case that other states fail to protect human rights and external states intervene on behalf of the humans whose rights are being disrespected).

But what mechanism of accountability does a human rights approach afford in the US context? Should we expect other states to intervene on behalf of those who fall within US borders, but are excluded from their human right to health care? Could we expect other states to do so, given the relative economic and political powers of the US compared to other states? Human rights grant rights without imposing sufficient correlative duties to fulfill these rights, or consequences for failing to do so.

Moreover, citizenship itself is an historically unjust practice. Citizenship is often the result of luck or unchosen circumstances for those born or not born into a given nation state, and citizenship for those on US soil comes with a history of territorial invasion, colonization, theft and enslavement of persons, and civil exclusions for women and minorities. Those who can legally immigrate also tend to have unique advantages in the form of having family members with legal status in the US who can sponsor them, access to higher education that can sponsor visas, or elite employment opportunities in which employers can sponsor the immigration process. In all cases the process requires sufficient financial resources.

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[53] Though again, from chapter one, I think we have good reasons to remain value pluralists, especially about health and well-being

Citizenship practices arguably run according to a similar logic as unjust property and ownership practices, from the way in which a state understands it control over its territory, to the ways in which we construct our citizenship as a possession: it is "my country" or "my citizenship."[54] It is something we hold and control as a good, not merely a status conferred through a recognition process.

At the same time, our initial citizenship in a place is part of the thrownness of our existence, an unchosen element. While I believe there are good reasons to reconstruct citizenship (as well as state sovereignty) according to relations rather than possessions,[55] this is not current practice as evidenced by the ways in which states do not recognize obligations to those who form relations with the place through participation in the state, rather than possession of its citizenship.

The case I want to build is that alleged universal rights actually stop at state borders, or are downgraded to civil rights. Not that civil rights are not important and valuable, but they are distinct from human rights in that they have a much more limited scope regarding to whom they extend (citizens, primarily) and who has responsibility for them (states, primarily). States are also the main

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[54] In the following chapters I will further consider the work of the possessive pronoun in Carl Wellman's analysis of "my" in Wellman, Christopher Heath. "Relational facts in liberal political theory: Is There Magic in the Pronoun 'My'?" *Ethics* 110 (2000): 537–562. Not all deployments of a possessive pronoun indicate ownership, such as when I talk about my child, my favorite food, or my hopes for the future. Yet I think that connections between territory and state and citizens to their state can rely on a framework of possession even though they need not do so. Avery Kolers, for example, talks about attachment to land, not possession of it, and Sam Fleischacker talks about good governance over territory, rather than ownership of it. See Fleischacker, Sam. "Owning Land Versus Governing a Land: Property, Sovereignty, and Nationalism." *Social Philosophy and Policy* 30.1-2 (Winter 2013): 373-403 and Kolers, Avery. "Attachment to Territory: Status or Achievement?" *Canadian Journal of Philosophy,* 42. 2 (June 2012): 101-123.

[55] There is a model of property acquisition from Locke that is closely connected to state ownership and control of property. Robert Nozick argues that the idea of just holding of territory requires justice all the way back to first acquisition, a problem for any theory of just territorial holding. For discussion see: Dodds, Susan. "Justice and Indigenous Land Rights." *Inquiry* 41.2 (1998): 187-205. I take this goal for justice to be impossible. This leaves at least two possible ways forward: one is to abolish all territorial holding (as well as private property), while another is recognition of historic injustice but allowing for positive law to nonetheless work toward more just institutions moving forward. I support the latter view. My position allows for both the continued ownership of property (though in the next chapter I argue for reasons that many property relationships need to be reconsidered or restructured) and jurisdiction (though not ownership) over territory. Part of my view includes radical reconsideration of the rights and obligations of those who have holdings of land, goods, or coercive ruling power, in light of the rights and entitlements of those who do not hold land, goods or social or political power. Extending rights to undocumented inhabitants of a state is part of this "radical," yet also more just, view.

agents accountable to and for human rights, and this produces practices in which there is not a clear obligation on the part of the state to those who are not its citizens.

We might note a general humanitarian duty to aid or rescue others, particularly in foreign states. A duty to rescue might be a strong obligation in instances when you are immediately confronted with someone seeking rescue, and you are in a unique position to respond. However, these features are rarely present when rights are not being protected in distant countries, and in which multiple external state actors could all equally well intervene. Such conditions tend to render any external state obligations as imperfect rather than perfect duties to respond.

The problem is only amplified when the persons to whom a state is not fulfilling a duty to rescue is a person inside its own borders, whether there legally or illegally. Arguably the 14th amendment of the constitution extends the legal protections of the constitution to all persons within US borders, whether or not they are citizens, though the amendment initially sets out protections of US born and naturalized citizens. The amendment states, in part: "No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws."[56]

The first clause of the sentence clearly limits intrusion on the privileges and immunities of citizens, but the second clause indicates protections that appear to extend to "any person" subjected to "due process of the law" and the third clause addresses all those "within its jurisdiction," or within its territorial boundaries, and that they are not to be denied "equal protection of the laws," of the US. The second two clauses use person, rather than citizen, to connote to whom the language extends, and therefore are not specific to citizens (or legal immigrants).

When there are particular laws on the books granting rights to health care, such as EMTALA, these do extend to all persons within US jurisdiction, in accordance with the 14th amendment. Yet, there is no constitutional right to health care as such, nor constitutional protection of a specific right to health.[57] The only group with a protected constitutional right to health care is

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[56] US Constitution, Amendment XIV, Section 1. https://constitutioncenter.org/interactive-constitution/amendments/amendment-xiv/

[57] It seems too broad an interpretation of life, liberty and happiness to infer that this entails a right to health in particular, though we might be inclined to think that some kind of health care would support the protection of life, liberty, and happiness.

incarcerated persons.[58] Two court cases, *Estelle v Gamble,* decided in 1976, and D*eShaney v. Winnebago County DSS* in 1989 enumerated prisoner health care rights under the 8th amendment's prohibition against cruel and unusual punishment.[59]

In practice the US does not recognizes obligations to protect those who live within, and often provide important services to[60] the state and its society. And there are not sufficient mechanisms for external state accountability. As alluded to earlier, even if external observers were to recognize exclusions of undocumented persons from rights and health care in the US as failures to uphold a human rights agenda, the retort is that the state is not obligated to those who have entered it illegally and that these individuals have citizenship elsewhere, in a state that is obligated to protect them.

We can say at least two things about this line of reasoning. One reply is that undocumented persons in the US may have fled a state that was failing to protect their rights; to recognize them as persons with rights; or without the capacity to provide for basic health goods or other rights and needs. At the same time, however, they may no longer be recognized as citizens of the state they left, in which case a related human right to statehood also needs to be protected and fulfilled.

The other reply is more complex, regarding the nature of obligation to those who are uninvited or have trespassed. The notion of trespass suggests that something is owned and controlled, with exclusive rights to use, and exclusive rights to reasonably exclude others. As discussed in the previous chapter, private property and exclusive ownership is a faulty practice, one that is built upon and often replicates unjust histories. For this reason, I think we could trouble the very idea of private ownership and control over states or territory that underpins the ascription of trespassing to undocumented migrants who cross into or live in the US.

I am not suggesting that nothing can be owned and controlled, nor am I suggesting that states ought to have open borders and not be able to dictate (to a reasonable degree, and ideally according to transparent and fair systems) who enters and remains within their territory. But we can think differently about the nature of trespass and the rights of the trespassed and alleged trespasser. Recall from the previous chapter that whereas Locke took a right to self-preservation to warrant a

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[58] Delgado, Melvin and Denise Humm-Delgado. *Health and Health Care in the Nation's Prisons: Issues, Challenges, and Policies.* Lanham, MA: Rowman and Littlefield, 2009, 53.

[59] Ibid., 52.

[60] As previously noted, the same percentage of households of undocumented adults have at least one full time working person as do households of legal immigrants and citizens. This means that undocumented persons are active participants of the economy and social structure as citizens and legal immigrants.

right to private property with exclusive control over said property, hence viewing self-preservation from an owner's perspective, Grotius took the right to self-preservation to override private property rights when a non-owner would need to access another's property in order to preserve herself.

Along these lines, it is unclear to me that we should treat any case of trespass as one in which the act of trespass is always wrong, or that it recuses the trespassed of any duties to the trespasser. This is complicated when we take the act of trespass to compromise our safety and security (rhetoric which is operational in current US anti-immigration talk). But many cases of trespass quite obviously do not infringe on our safety.[61] Similarly most illegal immigration does not compromise citizen safety.[62] There ought to be reasons that we, as decent people, as respecters of dignity, and as citizens whose own rights and benefits are often a product of luck, and a history of unjust practices, ought to support those who technically trespass against us, at least in cases where there is no threat posed, and perhaps even much benefit to gain.[63]

Part of my question then with regards to health care rights for undocumented immigrants in the US is: what would it mean to recognize others who are participants in our ethical worlds, even if not our citizenship realms, for their value, actions, and co-habitation within the same community? What responsibilities would we have toward other people under those conditions? To return to my notion of care from chapter two, there are tools of attention, affiliation and representation that we could embrace, in order to attend to and recognize the needs of others, affiliate with them despite not sharing markers such as citizenship, and represent them internal to our community and care relationships in a form of care justice.

It looks like a human right to health discourse falls short of holding states accountable toward those who live within its borders when it comes to undocumented immigrants, who do not possess civil rights accessed through citizenship, which I suggest functions in some key ways like property rights. A human rights framework from international law does not create sufficient external accountabilities from other states, nor does it provide a mechanism for existing citizens within the

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[61] For example, if one owns a large piece of property and a recreational hiker takes a shortcut through it or crosses in not knowing she has moved from public to private land.

[62] Studies show that while combined legal and illegal immigration continues to rise overall in the US since 1980, violent crime has steeply declined. Flag, Anna. "The Myth of the Criminal Immigrant" *The New York Times,* March 30, 2018. In a study of violent crime conviction in Texas in 2015, illegal immigrants were convicted of violent crimes at a rate of 56% less than native born US citizens. Ingraham, Christopher. "Two Charts Demolish the Notion that Immigrants Here Illegally Commit More Crime." *The Washington Post*, June 19, 2018.

[63] Though it is not because of the benefit that we ought to do this, I am not suggesting a quid pro quo.

state to hold their government accountable. Yet there is an opportunity to look within the mutually reflexive relationships we are in with others, what I will develop in the next chapters as our "ethical home," for both the source and accountability to uphold rights, including a right to health care.

To return to our Scenarios A and B, we might wonder: whose human rights are in question? In these cases, the pregnant person was (temporarily) eligible for health insurance via their unborn US citizen future child. The fetus was extended human rights. This is unproblematic if it were mere recognition of the fetus as belonging to the category of the human. Certainly, fetuses born to human parents are human fetuses. This stands separate to debates about fetal personhood, since human and person are not necessarily identical terms. Moreover, those of us concerned with health care justice for the mother and her future baby might support the outcome to improve prenatal and postnatal care for pregnant people and their children.

However, the fetus is not only granted human rights, it is also granted civil rights, which means granting it status as US citizen, even while still a fetus.[64] To be a citizen, the fetus would also need to be a separate, standalone person, from the person carrying the pregnancy. This comes with other dangerous implications for reproductive rights and health. For one, it codifies under US law rights of fetuses, in ways that conflict with other objectives of health care justice, particularly abortion rights.[65]

By creating parity between fetus and pregnant person in extending civil rights to an unborn child, it puts a pregnant person at risk of serious rights limitations including rights to bodily integrity and liberty, if any action undertaken in the name of bodily integrity or liberty poses a potential risk to this fetus with civil standing as a citizen.[66] Both fetus and pregnant person can be holders of human rights (with interests motivated by being members of humanity). But in the case of the

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[64] Something that Carl Wellman indicates is a theoretical impossibility though one that is nonetheless US law. According to Wellman, fetuses do have legal rights in the US legal system because the law has created them, yet "human fetuses are not possible right-holders." Wellman, Carl. "The Concept of Fetal Rights." *Law and Philosophy* 21.1 (January 2002): 65–93, 89. When considering human rights for fetuses, legal scholar Michelle Goodwin argues that "fetuses and embryos lack legal human identity in virtually all forms of law" (224), though she recognizes laws that extend health care to pregnant people via their fetus as a future unborn child nonetheless exist and paradoxically erode at women's rights in that they "primarily burden women and in unique and pernicious ways" (196). Goodwin, Michele. "If Embryos and Fetuses Have Rights." *Law & Ethics of Human Rights* 11.2 (July 2017): 189–224.

[65] Ibid., 115; George, Janel A. "Beyond a Beautiful Fraud: Using a Human Rights Framework to Realize the Promise of Democracy." *University of Baltimore Law Review* 42 (2012): 277-328, 308; Minkoff, Howard L, and Paltrow, Lynn M. "The Rights of 'Unborn Children' and the Value of Pregnant Women." *Hastings Center Report* 36.2 (2006): 26–28, 26.

[66] Minkoff and Paltrow, 26, 27.

undocumented pregnant person, only one of them has civil rights, and this is the fetus. When their interests or liberties conflict, especially though not exclusively regarding their right to health, how can this conflict be resolved? Or are they in intractable tension?

For example, what happens if the pregnant person faces a serious health risks, or possibly even death, by remaining pregnant? The need to terminate the pregnancy for the self-protection of the pregnant persons then conflicts not only with a fetus's interests in life or health, but also with its right to health. Being terminated means the fetus will no longer exist to exercise this right.[67] Alternately, if a pregnant person is carrying a fetus beyond 40 weeks gestation and there is now a heightened risk of stillbirth, it may be in the interests of the fetus's right to health to be delivered immediately. But it is also within the pregnant person's rights to health and bodily autonomy to not undergo unwanted surgery, if this is their preference.[68] Would this be overridden in a case according to which the fetus is recognized as a holder of civil rights?

While there is a lively debate as to when and if a fetus becomes a person, I grant that it is human whether or not it is a person, and I grant that it has interests even if it does not have rights.[69] Yet extending to a fetus civil rights to health as a way to honor its human rights to health seems to exacerbate, rather than resolve, debates about fetal personhood, while also illustrating that to fulfill human rights requires companion civil rights.

While a human right to health or even a human right to health care does not give us a satisfying way to address our undocumented pregnant patients' needs in Scenarios A or B, that does not mean that no conception of a right to health care could meet these patients' needs. One feature of health care as I have discussed it is an emphasis on various caring relationships (including but not exclusively between patients and medical providers). Health care is an inter-relational experience. A prominent view in maternal fetal medicine is that the pregnant person is the doctor's patient unless or until the pregnant person presents the fetus to the medical provider as a patient.[70] It is the act of

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[67] This is a plausible situation in cases where, for example, a person finds out both that they are pregnant, and they need immediate treatment for a serious illness, but the treatment is not compatible with carrying a pregnancy to term.

[68] Minkoff and Paltrow, 26.

[69] For example, Joel Feinberg takes "no stand" on the "complicated question of the point of the onset of personhood," but this implies that at some stage there is a "prepersonal fetus" that "has no actual interests," and "no actual harm can be done to it while it is in that state" but that at some point after conception the fetus becomes a person. Feinberg, Joel. *Harm to Others*. New York: Oxford University Press, 1984, 96.

[70] Chervenak, Frank A. and Laurence B. McCullough. "The Fetus as a Patient: An Essential Ethical Concept for Maternal-Fetal Medicine" *Journal of Maternal-Fetal Medicine*, 5.3 (1996): 115-119.

being brought into a relationship of care between fetus and provider that gives the fetus status as a participant in health care. But this relationship does not render the fetus a person with separate rights, or a right to health.

Furthermore, that the pregnant person is in relation to the fetus they are carrying may confer additional rights to, or obligations for, the protection of the pregnant person (rather than to the fetus itself). A legal statute in Colorado, for example, imposes higher penalties when a person is convicted of a violent crime against a pregnant person, and does so without recognizing standalone fetal rights.[71] Similarly we can recognize that there is a special relationship between pregnant person and fetus that makes them uniquely vulnerable, and this vulnerability could produce obligations for stronger health care relationships, without attributing rights to a fetus.[72] This is a feature of a right to health care, which focuses on the relationships of health care and acts of care. However, it is a flaw of a right to health, in which health is a status rather than a relationship.

While I agree with the ambitions of human rights, I do not see that human rights discourse is a fruitful path to achieve its designated aims. For those who object to my critique and stand by a human rights approach, the concept of an "ethical home" I offer in the following chapters is compatible with many desired outcomes of a human rights approach, but without drawing its normative force from a human rights justification.

The case of the undocumented immigrant patient highlights elements that a human rights view lacks, both in theory and in practice, and foreshadows elements of my own ethical home framework. By centering a right to care, it is not one's health status that is protected, but their access to elements of care. What is in the balance on this view is the level of care required as indexed to any particular case at hand, not to a perceived universal value of health. The case of the undocumented patient expects too much of human rights, yet human rights cannot attend to the likely injustice an undocumented patient will encounter by not having clear access to necessary medical care. Furthermore, the specifics of the case illustrate at least one danger of grounding a right to health

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[71] Minkoff and Paltrow, 26.

[72] Carl Wellman would say that the fetus as a non-independent entity does not have third party interests separate from the pregnant person (69). Though this might be true of the kinds of legal interest with which Wellman is most concerned, it is possible to understand a fetus as having interests, and be owed beneficence by a medical practitioner for example, though it is not recognized as a separate entity from the pregnant person (This is the view of Chervenak and McCullough, who see the fetus, only once presented for care and therefore having entered into a health care relationship, as being owed beneficence while the pregnant person is owed both beneficence and autonomy).

care related to the definition of the "human," with potentially dire implications for reproductive ethics.

Self-Ownership Rights to Health Care

To conclude this chapter, I turn to a very different realm of rights, though one also, and perhaps more directly, indebted to a connection with property rights and ownership. In the libertarian political tradition, in which the pendulum swings away from broad human rights that produce state duties to progressively realize positive rights, the state is minimal, and rights are negative. While there is debate[73] in the political philosophy literature regarding the centrality of the self-ownership thesis for libertarianism, and especially in the work of Robert Nozick, a version of the view that individuals are owners of themselves, and therefore have rights to exclusive control over themselves that entail negative rights to non-interference (from others and from the state) is nonetheless attributed to Nozick, and indebted to a Lockean framework.

Locke wrote about property in the person.[74] Owning property relates both to political standing and other rights claims for Locke. Ownership of property is tied to one's labor, therefore in theory it ties ownership back to one's body. Except that it was perfectly imaginable for Locke that one's ownership be produced through the labor of other people, and that other people's labor was in a sense owned by the property owner, especially by exerting control over serfs or slaves who work one's land.[75] Furthermore, even individuals with the standing of property owner are not themselves fully self-owners for Locke, because God is the ultimate owner.[76]

Nozick refers to Locke when he says that a notion of property "helps us understand why earlier theorists spoke of people as having property in themselves and their labor. They viewed each person as having a right to decide what would become of himself and what he would do."[77] He goes on to say that when the state taxes citizens it takes from them the product of their labor, which we

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[73] See: Brennan, Jason, and Bas van der Vossen. "The Myths of the Self-Ownership Thesis," in the *Routledge Handbook of Libertarianism* edited by Jason Brennan, Bas van der Vossen and David Schmidtz. New York: Routledge, 2017; Lowe, Dan. "The Deep Error of Political Libertarianism: Self-Ownership, Choice, and What's Really Valuable in Life." *Critical Review of International Social and Political Philosophy* (2018): 1-23; Sobel, David. "Backing Away from Libertarian Self-Ownership." *Ethics* 123.1 (2012): 32-60.

[74] Locke, Second Treatise, 19.

[75] Pateman, Carole. "Self-Ownership and Property in the Person: Democratization and a Tale of Two Concepts." *Journal of Political Philosophy* 10.1 (2002): 20-53, 25.

[76] Lowe, 9.

[77] Nozick, *Anarchy, State, and Utopia,* 171.

are to understand is their property. But because your body produces your labor, which produces your wages, for the state to garnish part of your wages through taxation would make the state "a part-owner of you; it gives them a property right in you. Just as having such partial control and power of decision, by right, over an animal or inanimate object would be to have a property right in it."[78] These comments, and one explicit use of the term "self-ownership," fall on two pages of Nozick's *Anarchy, State, and Utopia,* but have spun out a cottage industry of theory indebted to the "self-ownership thesis."

Brennan and van der Vossen suggest that self-ownership ought to be read as a "conclusion, not a premise" of *Anarchy, State, and Utopia,* and others have challenged or downgraded the influence of self-ownership on libertarianism's main claims. Pateman has argued that for political reasons, the connection between property and politics is best conveyed in the language of property in the person, not "self-ownership," because this best connects to the political valence of property.

Yet the concept of self-ownership nonetheless poses a plausible thesis about the nature of autonomy. Self-ownership suggests that individuals are the authors of their own bodies and persons, with exclusive control over them. This vision of individual control and autonomy has an appeal not only for libertarianism, but for both health care ethics, and for feminist ethics.[79] What I am going to suggest in the remainder of this chapter is that the rhetoric of self-ownership is appealing and pervasive, yet ultimately cashes out in worrisome ways that I think we ought to reject as either a premise or conclusion for a just health care ethic.

I have three key concerns about a self-ownership thesis justifying rights related to health care. The first should be obvious by now, that I take property rights to be a faulty and often (historically and presently) unjust institution. Again, I do not see these injustices as warranting throwing out the institution of private property entirely. All things considered, there are ways in which we can work within existing systems to protect some rights to control over goods. This includes potentially redistributing certain goods or redressing harms through reparation mechanism; reconceptualizing ownership in more relational ways, such as a relation to a good or a land, that requires good shepherding of the resource in question; and revisiting whether absolute exclusions of

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[78] Ibid., 172.

[79] Though it is complicated for feminist ethics in particular, which on the one hand endorses bodily integrity and bodily self-determination, especially for women who have historically been denied bodily self-determination, while on the other hand underscores the myth of individual autonomy in favor of theories of relational autonomy.

others from owned resources are warranted, or could be relaxed. However, my overall worry might be best captured by a concern about the nature of the "ownership" component of "self-ownership."

Would a reconceptualization of the very nature of property ease my concern? We can observe that in certain non-western cultures property is held in common, or that property has been traditionally a matrilineal institution, with women inheriting and controlling property and not men. Rosalind Petchesky has reimagined property in light of these kinds of cross-cultural observations.[80] Petchesky observed a common rhetoric of "owning" or "controlling" one's own body in the feminist movements of the 1990s, but worried that this only rehearsed patriarchal norms about property and control rather than radical feminist reimagining of norms.[81]

Her own project looks at "different cultural moorings" of property to "rethink the meanings of ownership, and thereby reclaim both a feminist idea of bodily integrity and a radical conception of property at large."[82] She contends that property did not necessarily have patriarchal connotations until Locke gave his patriarchal account of property.[83] In contrast, she notes that among the Daulo women from the highlands of New Guinea, women do not own their bodies, as much as they own the "reproductive and productive functions through which their embodiment is socially configured. For them, ownership is a relationship of care taking and collective authority over resources."[84]

Petchesky's model is similar to the view of territorial ownership as good governance of land, rather than control of land. Effectively the fundamental relationship in this view of ownership shifts from one of sovereign control to one of collective governing. She observes that "owning our bodies depends integrally on having access to the social resources for assuring our bodies' health and well-being" and thus "self-ownership and proper care taking go hand in hand with shared ownership of the commons."[85] Petchesky takes this argument as reason for all health-related goods, including social determinants of health, to be held in common. She claims that "we must reconnect our self-ownership to our right to communal resources."[86]

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[80] Petchesky, Rosalind Pollack. "The Body as Property: A Feminist Re-vision" in *Conceiving the New World Order: The Global Politics of Reproduction,* edited by Faye D. Ginsburg and Rayna Rapp. Berkeley: University of California Press, 1995, 387-406.

[81] Ibid., 387.

[82] Ibid., 388.

[83] Ibid., 393.

[84] Ibid., 390.

[85] Ibid., 403.

[86] Ibid., 403.

What happens if we extend her view that the goods of care, health care, and the conditions necessary to achieve care be held in common? While I think this could be the right conclusion to draw, it is built on wrong premises. The view remains indebted to ownership through labor (she cites reproductive labor as producing ownership rights) and there is a tension over what is uniquely owned and what is not. It looks like bodies can still be self-owned on her view, but all other conditions for bodily ownership need to be held in common. This creates an unclear division between what property can be uniquely controlled, and what property is meant to remain in common.

Why are bodies not held in common as well? Particularly when bodies are required to support the health and well-being of others bodies, as occurs in pregnancy? Reproductive labor generates ownership on her view, but where does this leave choices or rights not to engage in reproductive labor? Petchesky's view looks like it has precarious implications for reproductive rights, and who has the right to govern the body of a pregnant person. Does a pregnant person have an obligation to share their body in common with the fetus inside it once it engages in so-called reproductive labor? This same labor that makes one an owner is also doing a service for another, and for the community. How then is the reproductive body to be governed, and would it be governed within the commons as part of the collective interests of the society?

And though I agree with Petchesky's conclusion to place property in common, to an extent, my emphasis is on obligation to share what is owned, rather than to necessarily hold in common. Without additional terms and conditions for holding property in common, this approach does not help us to determine what is a fair distribution of the communally held resources, that in some cases will be limited and even scarce, which are necessary for one's health and well-being, or how to make sure those who most need resources can access the commons. And how do those with needs make claims on the goods? What does a claim look like? And what happens when those most in need cannot make a claim directly for herself? What is the role of the society to protect her claims on her behalf?[87] Even if the resources are commonly held, who accesses them and how? This returns us to the questions Daniels raises about just allocation of resources.

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[87] This concern also connects to my worry about the status of reproductive rights and choices, particularly if a fetus has interests in the commons, and the reproductive labor of pregnant people is part of what could be held in common, because then it looks like the collective can weigh in on the interests of the fetus by staking a claim to goods held in common on the fetus's behalf in potentially problematic ways for those who think pregnant people ought to be in sole control over their reproductive choices.

Part of my claim is that we can work within our existing practices of property, accepting what Thomson notes as the just transfer of property once acquired, even if we cannot account for the justice of the initial acquisition. In part, the injustice of the initial acquisition is what requires us to share what we own more widely, within our moral communities, and extend the vision of who is counted as those to whom I have obligations to share what I own or control.

The second and related concern about self-ownership is that self-ownership as absolute autonomy is a fiction. We do not merely possess absolute control over ourselves, it is a status granted to us by others. In a sense, our autonomy is produced through the process of others recognizing us as autonomous individuals. It also means that some of us are not recognized as autonomous, and a self-ownership thesis cannot help us achieve this kind of recognition without doing substantial political and social justice work to revise how we are regarded, or failed to be regarded, by both individuals or institutions. This concern might be best captured by a worry about the "self" component of "self-ownership."

This second worry has two elements. One is expressed in the Lockean notion of labor establishing ownership: some people's labor was not on behalf of their "self," but rather on behalf of the person who controlled them. So, serfs or slaves were not selves who could self-own. A certain class of persons (we can imagine male landowners in Locke's time) could be autonomous self-owning persons, but these persons failed to regard others as potentially self-owning.

In this way, self-ownership is not merely individual autonomous control, but is also a product of social relations and social systems that either regard some as self-owners while failing to regard others as such. As Anne Cudd notes, "self-ownership is a socially privileged identity that is not achievable by all. The self-owner must own some things aside from a body and have some skills or abilities in order to live as an owner," while those who exist in socially oppressed groups must "make their bodies available to the privileged at a cost much less than if they were social equals" through their labor.[88]

In Locke's time, one took property of land by laboring it. Yet serfs and slaves labored land that did not make them property-holders. Their bodies and labor were owned, and thus their labor

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[88] Cudd, Ann E. "Feminism and Libertarian Self-Ownership" in the *Routledge Handbook of Libertarianism* edited by Jason Brennan, Bas van der Vossen and David Schmidtz. New York: Routledge, 2017, 133. While Cudd says self-ownership is essentially a fiction, Pateman problematizes the self differently, noting that as a concept the self is more amorphous and less accepted than the concept of the person, another reason she defers to property in the person rather than self-ownership (Pateman, 23).

produced the property rights of someone who was already in a privileged position to be in ownership and control of both persons and land. Patricia Williams, who traces her own family's history of sale in the US in her book *The Alchemy of Race and Rights* also displays the feminist tension with the rhetoric of ownership when she engages the language of self-ownership to talk about feminist boundaries around the self in the same text.[89]

Another side of this worry about the concept of "self" in self-ownership is well-expressed by Cudd when she indicates the ways in which the "self" is "metaphysically constituted by its connections with other selves" and therefore cannot be "neatly separated from other selves."[90] This observation has implications for self-ownership and for libertarianism. Cudd thinks that a relational view of the self opens up a possibility for a relational view of libertarianism compatible with feminism. While she says that self-ownership might be appealing for accounts of bodily autonomy, it does not seem that the libertarian brand of self-ownership offers a strict boundary for protecting bodily integrity because it allows for boundary crossing as long as there is appropriate compensation.[91] According to the "cross and compensate" thesis, one's property can be infringed upon so long as one is retroactively extended appropriate compensation.

Such a view cannot square with a view of bodily integrity that would require individuals to grant permissions in advance of their bodily integrity being compromised. Cross and compensate may work with intrusions against externally held property: I spill something on your coat and pay the cleaning fee, or I drive on your lot and accidently run into your mailbox and knock it over so I pay to have it fixed.[92] It might be sufficient for a mundane situation related to bodily integrity as well: I step on your toe accidentally, and after the fact I show appropriate remorse by apologizing.

But in cases of medical or sexual ethics, where we value autonomy and bodily integrity and show respect for others' autonomy by seeking consent to engage them in a medical or sexual context, cross and compensate would be not only insufficient and inappropriate, it looks like it would also be wrong and potentially harmful. A doctor could not vaccinate me without my consent but then "compensate" me by deducting the fee for the vaccine and office visit from my medical

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[89] Williams, *The Alchemy of Race and Rights.*
[90] Cudd, 128.
[91] Ibid., 135.
[92] The cross and compensate thesis assumes or requires that appropriate amounts of compensation can be identified, and that individuals have the means to compensate those they have crossed. In practice neither of these may be the case.

bill. And a person could not perform a sex act on another person without her consent but then "compensate" her by buying her a meal, a luxury item, a necessity, or paying out a lump sum of money.[93] The former would be battery, and the latter would be rape.

One reply to the worry that self-ownership is a myth of autonomy, that is in line with Cudd's observation that we are always already in relation to others, is to merely adopt a view of relational autonomy but otherwise maintain the shape of self-ownership. Cudd does a version of this by modifying what the world "self" means, to say that the self is always connected to others and therefore when we read "self" we ought to read it as a "connected-self."[94] Cudd thinks that on this view of a connected self it is possible to reconcile libertarianism with feminism. She says that "maximal connected self-ownership rights look somewhat different, however, from the standard libertarian version of maximal atomistic self-ownership" for "the connected self must control its body in the sense that it must be able to preserve its bodily integrity against all forcible incursions; it must have the right but also the means to do so."[95]

The right to do so brings me to my third, and most significant concern, about the self-ownership thesis specifically for a right to health care. Self-ownership entails only negative rights. But what about rights to reproductive or any other form of health care? The appealing line of thought liberal feminism identifies in self-ownership as a thesis for autonomy runs that it keeps individuals, including women, as the autonomous agents of their own bodies. Cudd notes that it also suggests a way out of "lopsided, unchosen obligations," that might most often fall on women and other oppressed groups.[96] No one else is anyone's owner. I am less convinced of this latter point because self-ownership is founded on a system that allowed for certain people to be self-owners while others remained owned, often out of lopsided and unchosen circumstances.

But the thought that as self-owners we uniquely and independently control our own bodies would have positive implications for those who want to restrict my right to have an abortion for

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[93] The exception could be a rape case in which a civil suit was brought and damages were found to be owed, but this is a penalty for a harm, not compensation for an acceptable crossing.

[94] Cudd, 136 and 137. This view of autonomy is in line with prominent feminist conceptions of autonomy we might see in, for example: Friedman, Marilyn. *Autonomy, Gender, Politics*, New York: Oxford University Press, 2003. Mackenzie, Catriona and Natalie Stoljar, editors. *Relational Autonomy Feminist Perspectives on Autonomy, Agency and the Social Self*, New York: Oxford University Press, 2000; Meyers, Diana T. *Self, Society and Personal Choice*, New York: Columbia University Press, 1989, as well as Jonathan Christman's view of socio-historical selves, see: Christman, John. *The Politics of Persons.* Cambridge: Cambridge University Press, 2009.

[95] Cudd, 136.

[96] Ibid., 127.

example. It suggests that you, external person, can't have a say in my abortion. Becoming pregnant might be a lopsided and unchosen obligation that befalls a woman in a heterosexual sexual encounter and not a man, so in this regard, perhaps it is a way out of such asymmetrical obligations like Cudd suggests.

Yet we return to the issue of negative rights. Self-ownership generates rights of non-interference, but does nothing to protect those who, as Cudd rightly remarks, "cannot care for themselves."[97] This restriction to a negative rights framework poses a problem for positive rights to health care, whether from feminist, socialist, human rights, or other approaches. Again with reproductive rights example: if I need an abortion, I cannot independently fulfill that need. I can make the choice for myself, but I am reliant on others to execute the choice: either by performing a surgical procedure; or by developing, manufacturing, prescribing, and filling the prescription for, a medication that I can self-administer.[98]

This is true of all forms of health care. Health care is an inherently social enterprise, as I argued in chapter two and emphasize throughout. Health care is focused on care, which entails caring for others. It involves others doing things for and with us. Non-contentious medical procedures, like an appendectomy, or cancer surgery; treatment with antibiotics, or chemotherapy or hemodialysis; and administration of vaccines and other forms of preventative medicine all rely to varying extents on the care of others, both within and outside medical professions. (Cancer treatment might entail a good amount of family or friend caregiving when I am too weak to care for myself; vaccines require someone to develop and produce them, and hemodialysis might require me to rely on transport by someone else to get me to the clinic for my treatment and a medical team who provides it.)

If my rights are derived through self-ownership, then it looks like I do not have a right to health care, because no one is obligated to care for me or provide me with health care in the name of my rights, or my health. Public health measures become further obsolete on this ground, because they almost always entail some positive duties toward others, or the constraining of individual rights and freedoms for the greater good. This is the case with vaccine programs, in which it is not only beneficial to the individual to be inoculated against a disease, but it is also designed to create herd

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[97] Ibid.

[98] I am only considering safe, evidence-based abortion methods. In the absence of safe and legal medical abortions, pregnant people are forced to identify methods for self-aborting that are often unsafe, unproven, and can lead to harmful complications.

immunity that protects those who are immunocompromised or otherwise vulnerable, and cannot be inoculated themselves. Those vulnerable others might include: the very young, people on certain medications, or with allergies to vaccines, and who cannot be vaccinated; and those who are already ill and more susceptible to disease despite vaccination, such as with a flu vaccine that cannot provide complete coverage against a current flu season's flu strain.

My point in these pages is not to stage a full argument against libertarianism, so much as a central principle associated with it, that of self-ownership. There may be good reasons within political philosophy to accept a libertarian agenda. But there are also good reasons related to health care justice to challenge a theory that takes, as either a premise or a conclusion, strong notions of self-ownership to justify only negative rights. The view of health care I am promoting requires engaging with positive rights, a right to care, which I endorse not only as a duty to charity, rescue, or beneficence, but as a claim-right.

This view does not necessarily require a strong state to be the institution primarily responsible for these rights, however. In that way, the approach I take in the coming chapters is compatible with the libertarian conclusion for a minimal state. As I illustrated in the first part of this chapter, when the state is the primary agent charged with fulfilling a right to health care, there are manifold ways in which it can fail, especially when the right to health care runs counter to the rights the state understands itself to have with regards to its sovereignty, including rights to control membership, citizenship, and territory associated with the state.

My first aim in this chapter has been to suggest why a human right to health care faces at least two problems regarding to whom care is due. On the one hand, the category of the human risks extending care far too broadly. When the range of those owed care is all humans, it is difficult to address the needs of any specific humans, or to justify care to some over others. On the other hand, as I have suggested, human rights are protected and fulfilled at the level of states, and this renders them in practice to resemble a form of civil right. Thus, human rights in practice can generate exclusions of the most vulnerable from accessing health care: those who are stateless, undocumented, or otherwise without possession of citizenship that would entitle them to state recognition and protection.

My second aim in this chapter has been to show why a self-ownership or libertarian model for rights cannot accommodate the concept of care. It is, arguably, a model that can only accommodate health, but it leaves health up to the individual, as a series of choices over an individual's body that she can control. As discussed in chapter one, this kind of overly individualistic thinking, that relies heavily on concepts of autonomy and individual agency and choice, is common to concepts of health, but also faulty. Health is a product of luck, environment, and external social and economic conditions, often outside any individual's unique control. A self-ownership view will keep the most vulnerable people vulnerable, by not generating rights to and expectations of care from others, whether it is the state, individuals, or communities.

Moving into the final chapters, I propose an alternate model, a concept of an "ethical home," in which individuals are participants in, and therefore complicit in, the community in which they exist. Individuals participate in the formation (or necessary reformation) of their moral community's values and institutions, and the practices of recognition that confer membership in an ethical home. On my view, it is neither individuals nor states who have primary responsibilities for care. Instead, responsibility is generated by and shared among those with whom we share in ethical home-making. A framework of complicity makes individuals accountable as participants in a collective.

Ethical homes are the source and protector of rights to care, including health care. And through a complicity framework the members of ethical homes receive rights to care, but also have correlative duties to provide care. Thus individuals have clear responsibilities for care, but they are not only to themselves, or to those in their intimate and immediate circles of kinship or affection. Individuals have obligations to others as individuals complicit in the collective actions of their ethical home. This is not to say that states do not have roles within ethical homes. The state might be one level of home, though it is not the only viable one.

V

Complicity and Partiality

Up to now I have primarily made three claims. One, health care is a right, whereas health is an ideal. Two, a more appropriate definition of health care expands the scope of what constitutes health care, and yields wider rights than simply a right to access medical care. A right to health care also attends to social, political, and economic goods. And three, care itself is a value and practice that coheres moral communities, expressing their values which are enacted through the practice of care itself. I have further argued that this kind of care as a right is care justice. To provide a more complete picture of the kinds of rights and responsibilities entailed by my approach to care and health care, I have analyzed the concepts of rights, and in particular claim-rights and property rights. I have suggested that various ways into rights follow the shape and structure of property rights, including citizenship and civil rights, and this structure perpetuates inequities and injustices.

My analysis of human rights shows that while in theory human rights accrue universally to all humans, however difficult the term "human" might be to define, in practice they rely on the institutions of citizenship, states, and civil rights to protect and fulfill purported universal human rights. For this reason, I argued that human rights are at once too broad by theoretically applying to all humans, and too narrow by practically excluding those who do not possess citizenship, which becomes a good that can be owned and controlled (by some, but not others).

This logic of ownership does not only fail a universalist program like human rights, it also comes up short when what we supposedly own is our own body: my claim in the last chapter was that a self-ownership view of individual autonomy, especially, though not exclusively, when also connected to either a premise or conclusion of libertarianism, only entails a negative rights program. It protects against infringement on property, which in the case of self-ownership includes protection against infringements on bodily integrity. Yet the narrowly negative rights entailed by self-ownership views cannot offer a viable means for theorizing a right to health care, which necessarily includes a program of positive rights and obligations owed, in addition to negative rights of non-interference.

In this chapter I analyze the concepts of partiality and complicity that motivate my view of a moral community as an "ethical home." I elaborate on the concept of an "ethical home" in the concluding chapter. Though I started to discuss the concept of home in chapter two, in these final chapters I clarify what I mean by "home," and why "home" is a useful concept for the kind of moral community that I argue is both source of, and responsible for, the rights of those with whom we share our (ethical) home. Part of my unique intervention is to engage a framework of complicity to conceptualize individual participation and accountability within collectives.

Complicity in this analysis is a technical term. It is the assessment of intentional participation by individuals in a group, and intentional contribution by individuals toward shared goals of the group. A valuable feature of complicity, I argue, is that it not only affords a tool for attributing accountability for harms, but it also generates a framework for establishing responsibility to address harms. I argue for a specific account of complicity, that draws on and then modifies prominent accounts in the literature. I further argue that my own account of complicity is useful for thinking about individual responsibility within collectives when the collective is a moral community.

In this chapter I argue in favor of moral particularism when defining moral community. I claim that we are complicit in the moral self-definition of a particular moral community, and that this process both justifies and requires us to show partiality toward those with whom we participate in moral communities. This account of partiality justifies why we should pay particular attention to our moral community and its members. Additionally, it requires that we show partiality toward all of those internal to our moral communities, and not only those we take to be our immediate intimates, or those with whom we are in more traditionally structured special relationships.

In the next chapter I build on complicity and partiality to argue that complicity is a useful tool for defining and cohering particular moral communities in what I call "ethical homes." Importantly, I argue, rights and responsibilities are distributed among **individuals** as participants in a collective within ethical homes, and this attribution of both rights and responsibilities arises out of a complicity framework. I conclude this chapter by addressing an example of heart transplant recipient criteria, that I then pick up and further develop in the conclusion of the final chapter. The case illustrates implications of my view of moral community as complicit ethical homes for health care justice and how complicit ethical homes can and should practice care justice.

Individuals and Collectives

Why approach responsibility through the framework of complicity? We tend to think pejoratively about complicity: it assesses blameworthiness for wrongs or harms. So perhaps it is surprising that I think complicity is central to the making and shaping of moral community. Yet I take complicity to be particularly useful because it helps define a collective differently than other accounts of membership, and without certain pitfalls of those accounts. We might worry about how membership is, and is not, defined through in-grouping, out-grouping, recognition, failure of recognition, identity markers, or the historical inheritance of membership, such as when individuals are born into being citizens of a nation state and bestowed a package of rights. Central to my account is the idea that becoming a member, or being recognized as a member, of a group does not merely entail access to a preexisting package of rights (though there is an element of this at work). Instead it is the members of the group who generate and shape the rights that are then recognized by the group itself. And because members generate and shape these rights as participants in the group, they then have obligations as individuals and as part of the group collective to protect, respect, and fulfill these rights of its own making.

Certain problems for other accounts of membership will still be present in my account as well, particularly the challenge of recognition, and likely failures of recognition. We will, at times, fail to accurately or fully recognize members in our ethical homes. But I think my view can handle failures of recognition differently. In particular, my account can overcome failures of recognition that occur at the level of formal institutions, such as the state, with which I was preoccupied in the previous chapters. It does so by noting that whether or not we recognize our complicity in these failures, we might still be complicit, and therefore have obligations generated by our complicity.

Moreover, my account is designed to demand that individual members of a collective take responsibility for the group's practices, including responsibility for previous failures of personal or collective recognition, by acknowledging and then responding to these failures by revising collective practices. There is certainly still work to be done to create the conditions for recognition in the kind of moral community I am envisioning. While recognition has a necessary role in my account, for my current purposes I am largely bracketing whether a particular theory of recognition is operative in my view as a separate project, with separate considerations. On the view I am putting forth, rights and responsibilities are constantly in an iterative relationship with recognition. For the current scope, I think the shape of my account can stand regardless of how we later fill in a theory of recognition.

Of course, it remains a problem when rights (and the obligations they entail) are not recognized. This a problem for those excluded from the rights they are due, and it is a problem for those who are not meeting the obligations required of them. Yet once we have the shape of the view in place, and it is centered around complicity, there remains the ever-possible (and I will argue, required) potential for coming into seeing differently, and in order to rectify failures of recognition. Importantly, in order to rectify prior failures of recognition, my view does not necessarily require that we radically restructure our political practices in order to do so. Though it does require us to modify and reconceptualize many of our social practices, and this may lead to political change.

On this complicity account, we do not need to wait for a political revolution to change our practices. Nor do we need to become communitarians, socialists, communists, or whatever political label some might find worrisome. Instead, this account makes sense of our involvement with others differently. We do not need to be similar to, or identify with or into, others in the expected ways.[1] Nor is consent to participate in the group, a common theoretical stumbling block for political theory and democratic theory, central to this account. I argue that in key ways we are already enmeshed in a group whether or not we did, or would ever, consent. This is not to say that we are coerced into participation in the kind of moral community I imagine: we do make choices to engage or exit. Yet we also have to make sense of how we are thrown into certain unchosen circumstances, and then make choices within those circumstances for ourselves, and with others.

Next, I talk in detail about the particular account of complicity I am drawing on, the elements of it that I adopt, those I abandon, and how my analysis adds nuance to previous accounts of complicity. I also consider the terminology of “commitment” as it relates to complicity. The spirit of “commitment” is attractive, and without the pejorative connotations of “complicity.” However, “commitment” expects or assumes that an explicit commitment will (or can) be made among individuals. Such an explicit act of commitment is one that I do not think is often available to us. Moreover, it fails to address cases in which we fail to commit, but nonetheless should have obligations to others. Ideally, commitment is present in my own theory of accountability to a moral community, but it is not the first step, and it may not even be a necessary one, for my own view.

Complicity is appealing because it affords a way to think about how individuals and collectives are accountable, and particularly how individuals contribute to a collective. If a puzzle for collective or shared responsibility is how to attribute responsibility to specific agents, complicity responds, in part, to this puzzle. It provides a framework for why I as an individual must take responsibility for any other member of a collective. We see these kinds of questions arise in theories

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[1] I particularly like Angela Davis’s idea of “identifying into” instead of identifying with others, as it conveys the idea of a process that will always be incomplete. Identifying into is a kindred spirit to the type of affiliation I have in mind in my account of care and of moral community formation as a continual evolving process, the goal of which is never completion, like an asymptote. Davis, Angela Y. *The Meaning of Freedom: And Other Difficult Dialogues*. San Francisco: City Lights Publishers, 2012.

that analyze whether or how individual citizens are accountable for actions carried out by their state,[2] or in layperson worries about tax dollar spending and non-benefit to the individual: paying for roads if I don't drive, or schools when if I don't have kids, for example.

Regarding health care, we might imagine many individuals do not feel responsible for anyone else's health care. We can hear the refrain that other people "made their own choices" that render them in the health care situation in which they find themselves, whether that is being in relatively poor health, or being without sufficient access to care. We can imagine these "choices" including the choice to live some version of what is perceived as an "unhealthy" lifestyle; alienating family and friends who otherwise could have been caregivers when in a time of need; or not acquiring and saving financial resources to eventually direct toward health care costs when they arise.

Or we can imagine an individual's retort that someone else's health care is not only not my responsibility, but it a problem for "the state," or "they system," or "the hospital" to figure out. This suggests that it is the responsibility of a larger body to backstop health care needs, and that as individuals we have no direct responsibility as a part of this larger system. But what happens when the supposedly responsible institution in question appeals to its own limitations as reasons to deny or limit care? This occurs when the state, as I discussed in the last chapter, takes limited (or no) responsibility for non-citizens, or when the hospital concedes that it is hindered by the mechanisms of external institutions, like the state, and health insurance regulations, in pursuing necessary care.

While I argued in the second chapter that institutions are necessary for justice, I also suggested that care is necessary for justice. Institutions might not be the best caregivers, yet they are comprised of individuals: what is at stake is untangling the complex relationship between individuals and institutions, both of which, on my view, are necessary for the enactment of care justice. Complicity provides the connective tissue between individuals and various levels of more and less formal institutions, which are all also groups.[3]

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[2] This takes the form of questions regarding individual relationships to the state, and also individual relationships to each other within a state. For example: Caney, Simon. "Individuals, Nations and Obligations," in *National Rights, International Obligations*, 119-138. Routledge, 2018; Mason, Andrew. "Special Obligations to Compatriots." *Ethics* 107.3 (1997): 427-447; Stilz, Anna. "Collective Responsibility and the State." *Journal of Political Philosophy* 19.2 (2011): 190-208; van der Vossen, Bas. "Associative Political Obligations." *Philosophy Compass* 6.7 (2011): 477-487; Wellman, Christopher Heath. "Friends, Compatriots, and Special Political Obligations." *Political Theory* 29.2 (2001): 217-236.

[3] Here I am not talking about institutions only as practices, customs, or laws (such as the institution of marriage). My intention is to talk primarily about institutions as social organizations or groups. Yet practices, customs and laws are reflections of group values and also are constitutive of group formation and cohesion, so in this way institutions as practices feature into my conceptualization of institutions as groups.

Collective and Shared Responsibility

There is a distinction in the literature between collective responsibility and shared responsibility. Collective responsibility is the responsibility to act as or by a collective, where the group becomes the moral agent to whom action or accountability is attributable. For a group to be collectively responsible does not require than all or any individual members of the group are individually responsible.[4] The collective responsibility literature debates include considerations of: how collectives are formed; whether it is possible for a group to act, let alone intend to act as a group (or intend to not act, in cases where the non-action is what is morally relevant); if groups are morally accountable agents; and if they can be held as blameworthy (or praiseworthy) as a group.[5]

Shared responsibility is the responsibility of various members comprising a group, in which individuals are the moral agents who contribute to a joint project (act, harm, obligation, wrong, omission, etc.) that arises by virtue of being enacted by a group. In a shared responsibility framework, individuals are the primary agents, based on their intentions, voluntariness, control, and actions (or relevant non-actions) in bringing about something that occurs because it is enacted by a group, for which the individual participants are held praiseworthy or blameworthy.

For shared responsibility, questions remain about how groups come to be formed, and whether a group can intend together. Particularly we might wonder whether people who all appear to contribute to a shared act are in fact sharing the same intentions to produce this act. If participants do not share the same or similar intentions, and/or do not intend to participate in a group, are they sharing in an act or group in a meaningful way? Or is their joint participation (merely) incidental? On one view, shared responsibility can be an appropriate assessment when "a collection of persons displays either the capacity for joint action or common interest."[6] This does not mean that the collection of persons must agree or consent to joint action, or even that they intend anything beyond the pursuit of a common interest.

Shared responsibility hinges on something less metaphysically stringent than a group-as-moral-agent account of collective responsibility. Shared responsibility better reflects the lived

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[4] May, Larry. *Sharing Responsibility*. Chicago: University of Chicago Press, 1992, 38.

[5] Some examples from the literature include: Feinberg, Joel. "Collective Responsibility." *Journal of Philosophy*, 65 (1968): 674–688; Held, Virginia. "Can a Random Collection of Individuals be Responsible?" *Journal of Philosophy* 67 (1970): 471–481; Jaspers, Karl. *The Question of German Guilt*. Translated by E.B. Ashton, New York: Capricorn, 1961; May, Larry. *The Morality of Groups*. Notre Dame: University of Notre Dame Press, 1987; Pettit, Philip. "Responsibility Incorporated." *Ethics* 117 (2007): 171-201; Sosa, David. "What is It Like to Be a Group?" *Social Philosophy and Policy* 26.1 (2009): 212–226.

[6] May, Larry. *Sharing Responsibility*, 36.

experiences of trivial and non-trivial differences among individual group members that would make it difficult to otherwise meet the threshold of a properly constituted group. Shared responsibility also demands that each individual member of the group is in some way accountable for its actions, though this accountability need not be distributed equally.[7] Furthermore, "shared responsibility does not depend on the existence of a cohesive group since it concerns only aggregated personal responsibility."[8]Arguably, it is possible for a group that does not intend to be a group to still have shared responsibility when it finds that it has, perhaps despite itself, become a group.[9]

Importantly for the structure of shared responsibility, by retaining the role of individuals as agents comprising a group, intentionality and moral agency reside at the level of individuals rather than at the level of the collective. It looks like on an account of shared responsibility there are harms that are brought about because they are shared. Possibly these harms can only be brought about through the contributions of various agents. Such sharing of responsibility does not require, nor create, group cohesion. Arguably, the fact that we are always already interrelated and interdependent contributes to our shared responsibility with and for ourselves and others.[10]

My view follows from the shared responsibility literature, but carves out a new position within it. By engaging a complicity framework, I contend that it is possible to assess stronger claims of responsibility for both actions and practices on the part of individuals who are participants in a particular kind of group that in the next chapter I develop as an "ethical home." Complicity functions to not only assess or attribute individual action internal to a group action. Being complicit is also a way to conceptualize group formation and cohesion. I further argue that those who cohere in groups bound together by complicity are accountable for fulfilling rights claims of the group's members, and also have claim-rights that follow from their participation in the group.

There is an open question about unstructured collectives and aggregate individual acts (or omissions) from the shared responsibility literature that a standard framework of complicity cannot entirely resolve. The requirement for participatory intention in a complicity framework means that

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[7] May notes that "responsibility distributes to each member of the group" who "shares responsibility for a harm," (*Sharing Responsibility*, 38) but because shared responsibility is "aggregated personal responsibility" it does not mean that is a harm that is attributed to the group, responsibility for which is parceled out to each group member, but rather that the harm is built up from the aggregate and possibly varied actions of each participant (who may not even regard themselves as members of an identifiable group).

[8] May, Larry. *Sharing Responsibility*, 38.

[9] Held, "Can a Random Collection of Individuals be Morally Responsible?"

[10] May suggests that as individuals "we are all partially responsible for many defects of ourselves or the harms of the world" but it is also an error to view the self as radically free or radically individual "because our lives are interdependent with the lives of others" (*Sharing Responsibility,* 21).

so-called unstructured collectives are not appropriate targets for complicity assessments: individuals cannot be complicit in a group in which they do not explicitly or implicitly intend to participate. However, my approach to complicity is not primarily at the level of individual acts or omissions, but in the very formation of a group and its practices.[11]

My claim is that complicity is a tool for forming, and reforming (in the multiple senses of "reform") moral communities, and as such, some groups that might appear as unstructured because they do not fall neatly into existing institutional frameworks or socially-recognized schemas are in fact ones in which members are complicit in forming and maintaining. Therefore, they have responsibility for the practices that follow from the group.

Taking individual participation in collective action and responsibility as my focus, the framework for complicity offers a productive, though under-theorized, opportunity to develop the relationship between individual responsibility and institutional group practice. In my own view I talk about collective accountability for harms and collective responsibility to redress harms and take positive action, but I use the language of the collective to signify acting together as individuals participating in a collective, not to signify that the group itself is the moral agent.

I want to draw out one further distinction regarding moral particularity and special relationships that is relevant to the view I set out here. We might note that arguments for moral partiality, special relations, or particularism, including those that tend to follow from care ethics, justify why it is permissible to consider, care for, or fulfill needs of particular persons, in ways that we do not do for all persons.[12] Margaret Urban Walker observes that: "universalists can claim that what one is morally permitted or constrained to do in any case is what anyone else in a truly relevantly similar case is likewise permitted or constrained to do."[13] In other words, justice is treating

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[11] On this point I rely on Brooke Sadler's analysis of the distinction Rawls develops between justifying acts and justifying practices. Sadler, Brook Jenkins. "Collective Responsibility, Universalizability, and Social Practices" *Journal of Social Philosophy* 38.3 (2007): 486–503.

[12] Interestingly, Thomas Randall has recently noted that although both feminism and partiality literatures are concerned with special duties, they do not often speak to and with one another and has attempted to show why partiality is justified through "the values of care that are exemplified in good caring relations." While I take Randall's project to be in the same spirit as my own in attempting to align care and justice rather than treating them as two separate spheres, his view relies on a normative account of a "good caring relationship" I do not think his account generates sufficient support for the claim that there is a general obligation to provide care, on which he argument is premised. While I agree with the claim that there are obligations to provide care, my own account intends to justify why and how this obligation arises and who is accountable to whom according to it. I take both care and partiality literatures into consideration in this chapter to arrive at my own view. Randall, Thomas E. "Justifying Partiality in Care Ethics." *Res Publica* (2019): 1-21.

[13] Walker, Margaret Urban. "Moral Particularity." *Metaphilosophy* 18.3/4 (1987): 171-185, 172.

like cases alike. But we might then wonder: what is a truly relevant similar case? Walker sees universalists as trying to tease out features "potentially contributing to defining an agent's moral position" from those they view as "extra-moral motivations, non-moral concepts, or commitments presumptively antagonistic to doing what one ought."[14] These other features that are particular to the case at hand ought to be separated from the morally relevant universal considerations that motivate the morally correct path for the universalist.

However, there are many reasons we might have for "attachment and concern" that may not be "extra-moral" or "non-moral concepts." Some of these features are chosen roles that we knowingly enter into (parenthood, partnership, becoming someone's medical provider), while others are in varying degrees unchosen.[15] By defining what is moral and what is extra-moral, or what is cause for care and concern and what is not, a moral program, even a purportedly universalist one, has already carved out a particular position on what counts as moral concern and for whom. Walker describes this as the moral self-definition that occurs by expressing the particular values which provide the basis for moral choices.[16]

She further observes that appeals to universality can obscure bias,[17] and that we could reframe the ways in which attention is valued in moral matters so that we seek adequacy of attention, rather than uniformity of attention. In this way adequate attention is distributed to all, but this does not mean equal attention necessarily be paid to all.[18] Instead, appropriate attention is due in response to particular considerations, which we might say emerge through the self-defining work of the moral community.

Like Walker, my concern is less with the right to show particular consideration, and more with the obligation to show consideration to particular others. Walker has argued that we have to be able to identify what kind of commitments or attachments have moral relevance or make morality possible. My claim is that the shape of the moral community as an "ethical home" does this work, and the ethical home is a moral community formed through a framework of complicity. Following Walker, I favor moral relationships that allow for, and, moreover require, moral particularity.

Furthermore, I construct to whom we owe these particular duties of care, concern or responsibility differently than a traditional care-based ethic. Marilyn Friedman has suggested that we

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[14] Ibid., 173.
[15] Ibid., 174.
[16] Ibid.
[17] Walker, Margaret Urban. "Partial Consideration." *Ethics* 101.4 (1991): 758-774, 771.
[18] Ibid., 773.

have duties to our friends that "might not involve duties that are universalizable,"[19] and that social contract theories "may fail to uncover **special** duties of justice that arise out of close personal relationships the foundation of which is affection or kinship, rather than contract."[20] I agree that social contract theories overlook special duties and the nature of duties toward others.

But I do not limit these overlooked duties to be due only to those with whom we are in close personal relationships. My suggestion is that we have greater duties to particular others who may also be relative strangers. These duties are not grounded in direct kinship or affection, but out of much more generic (yet crucial) ways of being interrelated and interdependent. Some of these relationships emerge out of our reliance on the labor of others: preparation of the food we eat; driving the bus we take; cleaning the office where we work; providing nursing support to our aging parent in an assisted-living facility; delivering the mail we receive; fixing a leak in our roof; responding to our 911 call in an emergency. While these tasks might reflect someone's need for a job and income, they also arise out of concrete needs, and reflect values and practices that are essential to the functioning of our community. They are also various kinds of care. These mundane, commonplace, and non-affective ways of being related to others also make us complicit in the histories, presents, and futures of others.[21]

A View of Complicity

I adopt, and then modify, my view of complicity from that of legal scholar and philosopher Christopher Kutz, who has developed one of the few systematic frameworks for complicity in the literature.[22] In theorizing complicity, Kutz develops a technical definition of complicity that is distinct from the colloquial sense in which the term is often used. Colloquial complicity tends to describe the ways in which individuals act, or, perhaps just as often if not more, fail to act, such that their action or non-action implicitly contributes to a given outcome. Two brief examples shed light on this colloquial complicity: climate change and the #MeToo movement.

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[19] Friedman, Marilyn. "Beyond Caring: The De-Moralization of Gender" in *An Ethics of Care: Feminist and Interdisciplinary Perspectives* edited by Mary Jean Larrabee. New York, Routledge, 1993, 263.

[20] Ibid., 264.

[21] I take this view to build on the insight from May that individuals are interdependent, and that collective intention arises out of relationships between group members, where the structure of the relationships within the group generate shared intentions held by the group as a cohesive structure (May, *The Morality of Groups*, 65).

[22] Kutz, *Complicity.*

In the case of climate change, we might say that those of us who drive fossil-fuel consuming cars are complicit in global warming.[23] Our car-driving actions are not designed to produce global warming. Driving a car may be a necessary feature of our lives as currently designed, one that we take to be unavoidable. Yet our actions nonetheless contribute to carbon emissions that exacerbate harmful climate change. A second example of a colloquial use of complicity is seen in the #MeToo movement. When reports of sexual harassment are brought into the public attention, there is a growing awareness that individuals who witnessed wrongdoing (although they were not the direct cause or recipient of it) often failed to stop or report the behavior. In such cases, some have charged that these bystanders are complicit in maintaining a culture of sexual harassment.

These two examples uphold a dictionary definition of the term "complicity," which suggests that it is "passive compliance" in something that is often illegal or sinister.[24] In other words, we tend to deploy "complicity" to suggest association with, or passive permitting of, wrongdoing. Even though the dictionary definition of complicity is to be "involved knowingly" with wrongs, we might note that in colloquial parlance we often diagnose complicity in cases where the effects of our action or inaction are not immediately apparent to us. Sometimes this unawareness is negligent: we should have sought out, been aware of, or frankly paid better attention to the impacts of our (non)actions. But in other cases, our awareness is complete ignorance: perhaps we are not in an epistemic position to partially or fully comprehend the results of our (non)actions.

So, in the case of using a fossil-fuel based car (or any other consumption of non-renewable energy, or carbon-emitting activities) we might not always connect the dots between our choices and global warming. However, reports about the ways in which individual consumer choices contribute to greenhouse gases often include a refrain that as consumers we are complicit in negative impacts on the environment. Given such reports, we might say that what was initially ignorance transforms into negligence when we fail to pay attention to information that was readily available to us, and which we should seek out were we to be responsible consumers. Once we know this information, our epistemic position changes, and perhaps the nature of our responsibility does too, though this does not mean we were not responsible in our negligent or ignorant states.

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[23] Climate change is a frequent topic of collective responsibility literature, both Kutz and Sadler who I discuss in this chapter reflect on climate change, though draw quite different inferences from the case.

[24] "complicit, adj.". OED Online. July 2018. Oxford University Press. http://www.oed.com/view/Entry/250771?redirectedFrom=complicit (accessed October 6, 2018).

Colloquial complicity functions similarly to how individual contributions to global warming do: there is at best knowing involvement or passive compliance with behaviors that nonetheless have a part in producing climate change. But on Kutz's view, individual contributions to climate change do not correspond to a technical account of complicity. He characterizes individual contributions toward climate change as unstructured parallel actions. This means that no one individual is single-handedly responsible for harmful greenhouse gas emissions; it is only in aggregate that the harm is produced. Yet because the aggregate individuals did not intentionally participate in a group with a shared goal, this is not an example of complicity. A broad notion of shared responsibility might suggest that individuals contribute a share of responsibility for the aggregate actions of an unstructured group. But aggregate individual actions are conceptually distinct from structured group action, which is the target of Kutz's analysis.

Aggregate individual action does not meet the threshold for complicity on Kutz's view. This is not to say that such actions don't produce harm, or don't produce amplified harm in aggregate. Rather it changes the nature of who we hold accountable for harms and how. Part of the problem for making sense of these aggregate individual actions is that not only do the harms accrue through aggregate acts, but the response required to redress these harms also only obtains through a critical mass of individuals who stop acting in harmful ways. That you or I decline to drive our greenhouse gas emitting cars will not stop global warming through our individual isolated acts: it requires a collective response, or at least a critical mass of aggregate individuals who stop driving these cars.

Although a colloquial usage of complicity reveals something important about how we participate in and shape our moral communities, and appears to make space for the kinds of unstructured aggregate actions that we need ways to make sense of, it is important to distinguish it from a technical use of complicity. Colloquial complicity engages a notion of responsibility for individual choice, including one's actions as a bystander. It invites us to look deeper into the implications of our choices and how they contribute to larger systems. Yet it does not present a mechanism to hold individuals strongly accountable. I think there is good reason to engage a technical use of complicity, and to expand upon the conceptualization of complicity that has been offered thus far within the literature. One reason is that technical complicity makes levying strong rights claims possible, and generates responsibilities that follow from an assessment of complicity.

In reflecting on individual contributions to climate change, Brooke Sadler notes that not only do individual choices to drive (or to abstain from driving) cars make minimal difference to the overall effects of emissions on climate change, doing what others do (or not doing what others do not do) might be a mitigating factor for individual responsibility.[25] Yet Sadler distinguishes between justifying acts and justifying practices in order to begin to make sense of the nature of individual responsibility for unstructured aggregate outcomes. She says that "when one's action is performed within and as part of a practice, there are constraints on the action that do not apply outside of the practice; the action is covered by the rules of the practice."[26]

While her analysis does not resolve how individual actions contributing to an unstructured group could be assessed as complicit, it does offer a pathway to understand intentional participation in the group's practices itself as something in which its members are complicit, and therefore to analyze complicity in practices that promote or prohibit particular actions. I return to this thought when discussing community formation. Individuals are complicit in the practices that cohere a group. This complicity I the practices produces complicity in the moral community itself, or the "ethical home." Complicity in the practices of the group means taking responsibility for the practices that subsequently lead to actions (and omissions) by the group.

Kutz seeks an account of group actions. He takes up cases in which individuals may have contributed to collective harms or failed to contribute to collective goods. Kutz's project is to understand how individual actions are complicit in collective actions, therefore rendering individuals responsible. He formulates "intentional participation in a group's activities" as "the primary basis for normative evaluation," of cases of complicity because such intentional participation "establishes a special evaluative position, transforming prior social and ethical relations."[27] He draws a distinction, however, between an individual's intention to participate in a group and an individual sharing the intentions of the group. An individual can be intentional about her "contribution to the group" without necessarily sharing intentions of "the actions of the group as a whole."[28] Say someone plays guitar in a band, in which she intentionally participates, but does not share the intention with the group or as a group for the band to rigorously tour, sign a major record label deal, and achieve fame. For the guitar player, she contributes her guitar skills to playing music together, but not a collective ambition for fame.

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[25] Sadler, 490.

[26] Ibid., 495.

[27] Kutz, 67.

[28] Ibid. Kutz provides five features of joint action which include: the size of the group; the intricacy of the task at hand; the cooperative spirit among the group; the autonomy the individual agent has to perform a task within the group; and the level of influence any individual has over the overall group activities (Kutz, 68-69).

Importantly, neither coincidentally shared intentions resulting in similar but not coordinated actions, nor parallel actions toward similar (but not shared) goals are collective action. The latter was the case of our climate change example above. The former might graft onto why bystanders don't report sexual harassment. They might share the intention of avoiding relation, and the coincidental but not coordinated failure to report sexual harassment leads to a widespread, but not coordinated, culture of harassment. According to Kutz's view, without coordinated collective action there cannot be individual complicity.[29]

Again, it is worth underscoring that actions must be expressly shared or collective, and that group action is a prerequisite for the technical form of complicity under consideration. These features are not required for many of complicity's colloquial cousins. Collective action requires a shared goal among participants.[30] For individuals to be complicit when acting, they need to be intentionally acting together.[31] Additionally, an individual must intend to do her part to contribute to the collective act, for her actions to be complicit.[32]

Chiara Lepora and Robert Goodin provide another account of complicity that I will put in conversation with Kutz's. Their view reflects elements of both a colloquial use of complicity, as well as pitfalls of a technical use of the term. They do the additional work of parsing out a variety of linguistic distinctions relevant to the various uses and cognates of the term "complicity." Lepora and Goodin analyze "complicity" and its "conceptual cousins." I read their view of conceptual cousins as distinct from analogical concepts I discussed in chapter one. Instead, conceptual cousins share a family resemblance through their common etymological root of "cum" that means "together."[33] These terms include: acts involving co-principals that are not properly complicity (joint wrongdoing; co-operation, conspiracy, collusion); acts involving "contributors" that include a variety of types of qualified complicity (simpliciter, by collaboration, by connivance, condoning, consorting, and contiguity); and acts "involving non-contributors" that include connivance, condoning, consorting and contiguity without complicity.[34]

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[29] Ibid., 76.
[30] Ibid. It may be the case that those acting together have "strategically responsive" intentions, which are formed in light of "beliefs about other potential or actual joint actors" and their actions such that the choices and actions of others influence one's own choices and actions, but this is distinct from a shared collective intent to collectively act.
[31] Ibid.
[32] Ibid., 80-81.
[33] Lepora, Chiara and Robert Goodin. *On Complicity and Compromise.* New York: Oxford University Press, 2013, 36.
[34] Ibid., 52.

Lepora and Goodin focus on complicity in *pro tanto* wrongs and harms, particularly with regard to the work of humanitarian agencies who might be complicit in harms and wrongs occurring in the contexts of (and likely providing the reasons for) their interventions, in order to bring about overall good humanitarian acts. They are weighing the balance of the good and bad outcomes, all things considered, through the framework of complicity and compromise. In their reading, the law surround complicity offers the "most formal crystallization of moral views on these matters" though they note that law is not "particularly authoritative over moral matters."[35]

This legalistic view of complicity might be the most crystalized one currently available, yet I think it sells complicity short in terms of what it could offer as a conceptual framework. The legal category of complicity that connects it to a host of (also legalistic) conceptual cousins renders complicity a pejorative term: it is affiliated with sinister and illegal activity, with wrongs and/or harms, and with actions that compel moral condemnation and legal accountability. Complicity is comprised of "cum" to mean "together" and "plico" which means "to enwrap" and "to magnify."[36] Lepora and Goodin conclude that this etymological history of the word "characterizes contributory action that is 'wrapped up' in another's principal wrongdoing."[37]

Yet nowhere in the etymology of the word is it associated primarily or exclusively with wrongdoing or harm. These associations with wrongdoing are a feature of the term's historical use. At its roots, complicity suggests entanglement, and amplification of actions through togetherness. My view of complicity suggests a return to these roots, according to which complicity is a version of being interdependent[38] or entangled.[39] Such entanglement is arguably an apt description of our relationships, moral and otherwise, in which we already find ourselves, but which, as I stated earlier, we can revise and reform. This entangled view of complicity modifies the nature of intentional contribution to shared actions, because it in some ways accepts that we are always already participants in collectives. On my account, then, complicity is most helpful not to assess discreet acts or omissions for complicity (though it may still function in this way).

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[35] Ibid., 8.
[36] Lepora and Goodin, 41.
[37] Ibid.
[38] May, *Sharing Responsibility*.
[39] See Cherry, Myisha. "What an [En] tangled Web We Weave: Emotions, Motivation, and Rethinking Us and the 'Other.'" *Hypatia* 32.2 (2017): 439-451; Gruen, Lori. *Entangled Empathy: An Alternative Ethic for Our Relationships With Animals*. Brooklyn: Lantern Books, 2015; Richardson, Henry S. "Moral Entanglements: Ad Hoc Intimacies and Ancillary Duties of Care." *Journal of Moral Philosophy* 9.3 (2012): 376-409.

Complicity is most useful to establish the parameters of the moral community by assessing the complicity of individuals as participants already thrown into interdependent relationships, who nonetheless make intentional choices to act in ways that reflect, or implicitly rely on, this interdependence. Complicit participation is what establishes the normative practices and cohesion of a moral community. What follows from this complicity, then, is a set of rights and responsibilities that flow from the complicit moral community. First, I need to say more about the technical concept of complicity I endorse, before fleshing out the mechanics of how it functions to cohere moral community.

The technical use of "complicity" is what I mean by "complicity" unless otherwise qualified. This technical definition adds the feature of intent that is absent from a colloquial use. Importantly, complicity requires shared intent among individuals to contribute to a group, and to work toward a shared goal. While this raises questions about what it means to share an intention,[40] and how this can be assessed, my view takes a lower minimum standard for shared intention than Kutz's because mine is a framework for moral, not legal accountability. I accept that there can be demonstrable shared intentions. Such minimally shared intentions may yield other required, even if not also intended, shared objectives.

The reason I want to argue for and retain a technical use of complicity is that on my view it not only allows us to attribute individual responsibility within collective accountability for identified harms. It additionally grounds individual duties to address harms. Because individuals are complicit in the creation and perpetuation of the collective, duties do not accrue only to the collective as a collective, but also to individuals comprising the collective.

I call this the two sides of complicity, that assess both complicity in wrongs or harms, and complicity in taking responsibility for right action. Most often complicity is a negative assessment, one merely of blameworthiness. But the same structure that leads to attributions of individual blame within group action can also produce individual responsibility for right action. This is the positive side of complicity. By identifying individuals within a relevant collective as responsible for collective harms, there is then also an accountable group who is obligated to morally respond to these harms.

Arguably, Kutz sets a high bar for what can be assessed as complicity. He is a legal scholar concerned, I take it, with the possibility for criminal prosecution of those responsible for collective harms. This is part of the reason intent plays such a key role in his framework for complicity. While

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[40] Gilbert, Margaret. *Sociality and Responsibility: New Essays in Plural Subject Theory*. Lantham, MD: Rowman & Littlefield, 2000.

the bar is high, I endorse his framework as a useful one for thinking about how collectives themselves come to be formed, and the actions that follow from this intentional formation of, and participation in, groups. Mara Marin's critiques of Kutz and her positive view that emphasizes "commitment" over "complicity" provides nuance to the implications and limitations of participatory intention for individual participation in a group.

Marin ultimately takes much of what Kutz is doing as in line with her own project, but rejects his account of "participatory intention," arguing that in the face of oppressive structures, our participation is not even in a weak sense intentional, although we have obligations to collective action in the face of such oppressive structures.[41] Kutz defers in these cases of oppressive structures to the idea that background structures are only loosely understood as "quasi-participatory," and therefore are not a basis for accountability "because there is no specific project to which individuals contribute."[42] In contrast, Marin thinks that we have inherited unintentional participation in structures like gender (which is ingrained, received, or internalized, but we nonetheless have a role in reinforcing these structures when we, also unintentionally, participate in them through actions like shopping for clothes that conform to gender norms).[43]

I endorse Marin's point that we have inherited unintentional participation into norms and structures. Yet I take her point to be a call to intentional action to reform practices if we find them to be unjust or oppressive, particularly those in which we are complicitly implicated. If we find gendered clothing to be an oppressive structure, then we can reject gendered dressing as an individual act, but also can engage this act as a means to reform the practice itself.[44] An important feature of my view is that complicity works in two ways. It entails attributability for harms, but also taking responsibility for change.

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[41] Marin, Mara. *Connected by Commitment. Oppression and Our Responsibility to Undermine It.* New York: Oxford University Press, 2017.

[42] Kutz, 186.

[43] Marin, 10.

[44] Marin seems to think that the fact of having gendered clothing options is oppressive. We might say that expectations for people to dress in ways that reflect a conventional notion of gender is what is oppressive, and perhaps we think that having gendered clothes in the first place is what sets this expectation. I am not sure. Having clothing that fits your body is important, and a structural lack of access to clothing that fits (which could be due to sex differences in body structure, or simply due to variation in body size) does seem oppressive. As of the time of writing, we are witnessing gender norms shifting. A children's book by Keith Negley from 2019 called *Mary Wears What She Wants* upends expectations that there are "boy clothing" and "girl clothing." It starts out saying that "once upon a time (but not too long ago), girls weren't allowed to wear pants. Can you imagine?" Children reading this book now might grow up in a world where they do not feel burdened by gendered expectations of dress at all. Some of this might be due to the proactive work of people like Marin (and Negley) to modify these practices.

Because we are always already complicit in certain structures, and cannot **not** participate in them, even if it is only through quasi-participation given its initially unchosen nature, I think we can engage the concept of complicity to positively guide and require action that transforms harmful practices. In this way, our complicit participation in the practices of the group requires us to take responsibility for reforming the actions of the group.

Marin thinks that the concept of commitment is more successful than Kutz's "participatory intention" because "individual responsibility for structural injustice is similar to obligations of personal commitment."[45] For Marin, "on the view of structures as commitments… as long as there is an unjust structure that both structures my actions and is perpetuated by them, I am responsible for the injustice of the structure because it puts me in an unjust social relation… to another person… and that makes me responsible to change this relation." This includes owing it "to those who occupy the subordinated positions to redress the injustice, not (only) because there is injustice, but because my actions perpetuate it."[46]

There is a nagging problem of being responsible for things we did not choose. Marin notes that we tend to agree that we have obligations to save a drowning child, if it is not a risk to ourselves, and we tend to agree that if we can help a refugee from a war we had nothing to do with, we should.[47] On conventional views of obligation, the refugee case might be more controversial: what is the nature or scope of help we ought to provide to this refugee who is likely not immediately in front of us like the drowning child is?

Marin claims that we actually have deeper obligations to the structures that appear unchosen to us because we contribute to their perpetuation, therefore we are involved in them in ways we are not involved with the drowning child or refugee.[48] She concludes that the source of the "obligation we have to transform an unjust structure - or, in the case of a just structure, to maintain it" lies in action, because "structures are created in action."[49]

Marin's amendments to Kutz's view concord with my two-sided account of complicity: complicity as responsible both retrospectively and prospectively. I take her emphasis on the unchosen nature of our world, and obligations we nonetheless have despite it, to be crucial premises

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[45] Marin, 11.

[46] Ibid., 11-12.

[47] Ibid., 13.

[48] Ibid., 13.

[49] Ibid., 16. Though she also notes that even our individual actions are not entirely in our control because they are interpreted and co-created by others who make meaning from our actions alongside us (Marin, 13)

in my own account. Her project to revise Kutz's view of quasi-participation (such as in social structures that are received) that for Kutz creates only a weak obligation in order to generate much stronger accountability for participation in social structures is a fair and important undertaking. Marin persuasively argues that weaker accountability for things less in our control is problematic because structural injustices are some of the greatest injustices we face, and they are deeply in need redress.[50]

I am on board with this proposition, and her emphasis on the unchosen nature of our world, which does not remove our obligations merely because aspects of our lives and context are not chosen by us. However, I do not agree with Marin that "commitment" functions better than "complicity" to arrive at such responsibility. For Marin commitments are "relationships of obligation," which "bind unconditionally," yet "allow us the freedom to define, negotiate, and alter our obligations."[51] In the next chapter, I detail why commitments do not function in the way she intends.

Complicity is the right way to think about individual participation in moral communities because complicity is a mechanism that generates individual rights as a member of a moral community in which one is complicit. Moreover, we should understand complicity as two-sided: complicity is to be individually responsible within a collective, both retrospectively and prospectively. I do not think we need to give up on the possibility for complicity to meet the demands of the project of redressing structural injustice. Complicity entails individual responsibility to address, and when necessary redress, rights claims of others with whom you share in the moral community.

Additionally, complicity best reflects the nature of what Marin is characterizing as "commitments." In the next chapter I expand on this point, and articulate why this kind of complicit moral community is an "ethical home," in which we are bound, and in which we have obligations to, as Marin says, "define, negotiate, and alter our obligations," through what I understand to be the moral process of ethical home-making. In addition, I suggest that complicity in ethical homes is a better framework for administering care justice, and just health care, than the state-based or human rights-based accounts I considered and rejected in previous chapters. I touch on four potential critiques of this view and reply to them, before returning to the case of heart

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[50] Marin, 12.
[51] Ibid., 31-32.

transplant recipient criteria in US policy and practice that I turn to now, and examine in light of my claims regarding complicity, for the remainder of this chapter.

Heart Transplant Case

Much of what I have said in this chapter, and in the chapters leading up to it, has been largely conceptual. Working through a concrete example of health care practice and policy, how patients are listed to be heart transplant recipients, I now trace how these concepts could cash out in actual health care delivery, particularly in light of my expanded concept of health care.

In presenting the case, I intend to show that the listing criteria for heart transplant recipients is meant to best use the scarce resources of donor hearts. However, it includes controversial and possibly unjust psychosocial criteria that, while responding to medical objectives, may not best reflect overall care and health care obligations, particularly following the expanded account of health care I have already offered. In the next chapter, after presenting my additional arguments in favor of complicit ethical homes, I return to the case to argue that complicit ethical homes could take at least one of two approaches made possible by the shape and structure of an ethical home in order to either revise heart transplant listing criteria, or the practices that would better support the psychosocial criteria, in order to bring the criteria, the practices, or both, in line with care justice.

When writing in the early 1980s Norman Daniels turned to the case of heart transplant at the conclusion of *Just Health Care* as an example of the intersection between philosophy and public policy. He asked if justice required the funding of heart transplants, which were at the time still experimental surgery.[52] Daniels did not take a conclusive stance, noting the various aspects of justice that come into play when asking and answering such a question. In effect, he concluded that heart transplant policy is a non-basic case, and using a basic framework for health care justice, such as his, cannot be neatly applied to non-basic cases. He conceded that his account "does not give us lessons in strategy for reform."[53]

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[52] Daniels, *Just Health Care*. Although heart transplantation first occurred in 1967, they only began to be routinely practiced starting in the 1980s, and then faced a decline in the mid-1990s due to shortages of available organs. de Jonge, N., Kirkels, J. H., Klöpping, C., Lahpor, J. R., Caliskan, K., Maat, A. P., Balk, A. H. "Guidelines for heart transplantation." *Netherlands Heart Journal: Monthly Journal of the Netherlands Society of Cardiology and the Netherlands Heart Foundation* 16.3 (2008): 79–87. Transplants are managed at a national level, however the article from the Netherlands contexts notes trends in transplant frequency that were true internationally from the 1960s to the end of the last century.

[53] Daniels, *Just Health Care*, 228.

While solid organ donation amplifies questions of justice and the balancing of scarce resources like donor organs, which are often available only due to the death of another person,[54] as well as high levels of technical skill, financial and social capital, and ongoing research and technology, we might wonder if any cases of actual health care provision could be non-basic. Nonetheless, Daniels takes heart transplantation to raise the kinds of questions which require an applied philosopher to recognize limits between theory and the applied context in which she is attempting to mobilize her theory.[55]

Given my commitment to practices informing, not only reflecting, theory, I take Daniels's observations regarding the limits of his basic theory to be an invitation to do not only tactful applied work, but also do further conceptual work that can align theory and application in ways Daniels acknowledges his own theory falls short.[56] It is one thing to say that the practical implications of a theoretical finding will be difficult, or will require radical change. It is another to say that the theory cannot accommodate the case, or the case cannot fit with the theory.

My aim is to show that building on partiality and complicity as ways to define and conceptualize the moral community, these concepts can be mobilized to address shortcomings in contemporary heart transplant patient listing criteria. The landscape has changed since Daniels was writing in the 1980s, and solid organ transplant programs are no longer experimental. But questions of justice persist in the allocation of resources involved with organ transplant, in both obvious and, as I will suggest, less obvious ways.

Daniels's question regarding the public financing of heart transplant illustrates the obvious justice question about organ transplant programs: how to justly distribute scarce resources? There are fewer available hearts than there are patients awaiting transplant. According to the United Network for Organ Sharing (UNOS) which oversees all solid organ transplantation in the United States, there are currently over 100,000 people in need of a solid organ transplant, of which about 75,000 are actively listed as candidates to receive an organ. Just over 36,000 transplants were done in

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[54] Although kidneys can be donated by live donors, who undergo surgery to donate one of two functional kidneys, and work is being done regarding live donors for liver transplant due to the ability of the liver to regenerate. Still, live organ donation is also a serious undertaking that relies on many other resources, including the availability of a willing donor.

[55] Ibid., 229.

[56] Ibid., 229. I take it Daniels is explicitly appealing to the need for further attention to ideal theory in non-ideal practice. My own approach is a kind of ideal theory in the sense that it offers a broad general framework, with the anticipation and expectation that the theory only exists inside non-ideal conditions, and is designed to be responsive to non-ideal contingencies.

2018, with roughly 60% of those being kidney transplants (which can be live donors, as opposed to requiring a donor death). So far in 2019, 9,500 transplants have been performed in the first quarter of the year, resulting from organ availability from 4,500 donors.[57] If this pace continues for 2019, approximately 38,000 people will receive transplants, or about half of those actively listed, and only one third of those who are in need of an organ.

Organ donation most clearly rests on the principle of justice in biomedical ethics when taking a principle-based approach. Although, autonomy, beneficence, and non-maleficence all also come into play. A patient should make informed decisions about her possible transplant, reflecting autonomy. The objectives of transplant should be overall beneficial to her, and harm should be avoided, reflecting beneficence and non-maleficence.[58] Transplant candidate listing criteria reflects these principles by: requiring potential candidates to demonstrate understanding and capacity to make decisions; listing candidates in the order of those who will most immediately and urgently benefit from transplant; and by not listing candidates for whom it is anticipated that major surgery and recovery might in fact cause harm.

The question of justice underpins the idea that the patient who will most benefit from the resources (the donor heart itself, and the various medical and non-medical resources that will be mobilized to ensure a successful transplant) ought to have priority in receiving a donor organ. Daniels describes a two-person case, in which one person is clearly better suited to live a longer and healthier life in light of a transplant, and thus between the two candidates, justice would have her receive the heart in question.[59] These kinds of two-person cases risk misunderstanding what the goods are to be distributed. They are not merely material goods, although the concrete good of a donor heart, and the medical resources the process requires, are crucial to transplantation.

There are also relevant social goods in question, as Daniels made clear by asking if public funding should support heart transplantation. Factors beyond merely whether person A or person B receives a heart come into play when thinking about justice. Questions about funding for transplant programs, whether these programs are a good use of public resources, and whether transplant supports public health justice, when less costly but more inclusive health care initiatives might be

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[57] United Network for Organ Sharing "Transplant Trends," April 2019 https://unos.org/data/transplant-trends/

[58] Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. New York: Oxford University Press, 2001. Principle-based approaches are not the only way to assess questions in bioethics, but they are a common one and therefore a helpful starting point for ethical reflection.

[59] Daniels, Norman. "Four Unsolved Rationing Problems A Challenge." *The Hastings Center Report* 24.4 (1994): 27-29, 27.

better uses of health care spending, all things considered, hang in the balance. Yet there are even less recognized social goods that are called into question, and possibly the (re)distribution of recognition itself in terms who we recognize as worthy recipients of an expanded notion of health care that entails social, political and economic care.

I am not going to take up whether transplant programs are right uses of resources all things considered, or best express health care justice. I will assume that as a society in the US, the existence of the practice of organ transplantation, including heart transplantation, suggests it is of value within our community, and that it is a practice that will not be concluded in favor of redirecting health care spending, research and development, and personnel time currently spent on transplant to other health care issues. But I do think that for transplant programs to be brought more in line with a principle of justice, certain of the criteria for transplant candidacy ought to be revisited.

Heart transplant criteria are designed not merely to weight who ought to receive one heart between two potential recipients. They take into account a variety of factors that would render a patient a more or less successful transplant candidate. Success is revealed in both short and long-term outcomes for transplant recipients. The hope is to improve patient quality of life and outcomes,[60] while also doing justice to the resources themselves, particularly the good shepherding of a donor heart, given the scarcity of the resource and perceived sacrifice a donor has made to donate the heart. All of these elements rationalize prioritizing transplants with the highest likelihood of success.[61] Given these aims, the "selection process to determine which patients can benefit from transplantation is dynamic and requires careful assessment of multiple factors on an individual basis."[62]

Due to the complex, and justice-driven aims, of transplant programs, we see heart transplant criteria reflecting both medical facts and history, as well as psychosocial aspects. Potential candidates must meet medical criteria that, while acknowledging they are sick and declining in light of the heart failure that makes them a potential transplant candidate, is balanced with their potential for resiliency and recovery after transplant surgery. Such criteria include: absence of certain co-morbidities; being

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[60] Lee, Sook Jin, Kyung Hee Kim, Suk Keun Hong, and Shelley Hankins. "Evaluation of a Heart Transplant Candidate." *Current Cardiology Reports* 19.12 (2017): 133.

[61] Gaffey, Ann C., Stacey L. Doll, Arwin M. Thomasson, Chantel Venkataraman, Carol W. Chen, Lee R. Goldberg, Emily A. Blumberg, Michael A. Acker, Francis Stone, and Pavan Atluri. "Transplantation of 'High-Risk' Donor Hearts: Implications for Infection." *The Journal of Thoracic and Cardiovascular Surgery* 152.1 (2016): 213-220. Separately, we might wonder if dead donors have indeed made a specific sacrifice to donate their heart – it is unlikely their death was in any way motivated by the intent to donate a heart.

[62] Lee, Kim, Hong and Hankins.

in a healthy weight range; not using tobacco, drugs or alcohol; being under 70 years of age (although being above 70 years of age is a relative, not absolute, contraindication for some programs); and demonstrating the ability to comply with preoperative and postoperative medical care and guidelines.

Medical indications lead a potential recipient to be listed higher or lower on the priority list, and some contraindications for transplant will be absolute while others will be relative. Though there are overall guidelines developed internationally for transplantation, individual transplant programs can set specific policies for how they will determine whether and where to list a potential transplant candidate. In the case of Johns Hopkins' heart transplant program, age, HIV, a recent (within 5 year) history of cancer, and being an active smoker are all absolute contraindications for heart transplantation. Relative contraindications for their program include certain health conditions, as well as inability to commit to organ transplantation, and the absence of either short or long-term psychosocial support.[63]

International transplant guidelines developed in 2006, and revised in 2016, note that:

> heart transplantation should be reserved for those patients most likely to benefit both in terms of quality of life and survival. The major ethical argument for the use of psychosocial criteria is the same as for medical criteria, such as allocating scarce donor organs to those most likely to benefit. However, there are fewer data on the reliability and validity of psychosocial criteria and on the ability of such evaluations to predict outcome after transplantation. Care must be taken to ensure that psychosocial factors predictive of outcome are not confused with judgments of an individual's social worth.[64]

While the guidelines acknowledge that not all transplant programs "insist on the involvement of a psychiatrist, psychologist or other mental health professional in the assessment of every patient," programs do take into account a psychosocial evaluation. The aim of this evaluation is to "identify whether the patient has family or friends who will provide support through what is obviously a difficult period and who are willing to make long-term commitments for the patient's welfare."[65]

When surveying various practices of psychosocial evaluation in transplant listing, the results showed "wide variation in the reasons for excluding patients from transplantation based on psychosocial grounds."[66] The 2016 updated heart and lung transplant guidelines reflect that these

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[63] Johns Hopkins "Heart Transplant Patient Selection Criteria." Accessed April 19, 2019. https://www.hopkinsmedicine.org/transplant/referring_physicians/patient_selection_criteria/heart.html

[64] Mehra, Mandeep R., et. al. "Listing Criteria for Heart Transplantation: International Society for Heart and Lung Transplantation Guidelines for the Care of Cardiac Transplant Candidates – 2006." *The Journal of Heart and Lung Transplantation* 25.9 (2006): 1024-1042, 1043.

[65] Ibid., 1035.

[66] Ibid.

recommendations arise out of data with a "C" level of evidence. This level of evidence reflects general consensus in the field and expert opinion, but does not reach the level of verified randomized control studies that would provide empirical evidence confirming these recommendations result in the outcomes they anticipate.[67]

Care Justice and Heart Transplant

In direct practice, what does guidance regarding psychosocial criteria look like for potential transplant recipients? In the Vanderbilt University Medical Center heart transplant program, materials provided to heart failure patients about "being evaluated for heart transplant" remind patients that a heart is a valuable resource and that to go through the transplant program you must have outside support. This includes a requirement for two available caregivers to support throughout evaluation, wait-listing, transplant, and recovery processes. Caregivers must be over the age of 18, generally reliable, and able to drive (to take patients to and from appointments, so presumably they are also required to have access to a reliable vehicle).[68] The psychosocial evaluation includes a determination of whether or not a potential transplant candidate has adequate social support to undergo transplant, and this factors into whether or not a patient will be listed for a heart.[69]

In addition to the psychosocial resources, patients must have adequate financial resources to undergo transplant. While some programs are covered under Medicaid, Vanderbilt University Medical Center, for example, makes explicit to patients that the transplant program's participation in Medicaid is contingent upon periodic auditing, and that this relationship could be discontinued in the future. Transplant recipients are reliant on life-long immunosuppressant drugs that currently cost $60,000 per year.[70] The high cost of the required medicines means that patients must have adequate prescription drug coverage (or be able to self-pay an amount of money that is going to be exorbitant for most people). Patients are also advised to consider additional non-medical expenses they or their

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[67] Mehra, Mandeep R., et. al. "The 2016 International Society for Heart Lung Transplantation Listing Criteria for Heart Transplantation: A 10-Year Update." *The Journal of Heart and Lung Transplantation* 35.1 (2016): 1-23, 4.

[68] Vanderbilt University Medical Center Heart Transplant. "Being Evaluated for Heart Transplant: A Guide for Patients and Families," https://www.vanderbilthealth.com/transplant/27726 accessed April 18, 2019, 5.

[69] Ibid., 11.

[70] Ibid., 27.

caregivers may incur, and encouraged to do external fundraising for transplant-related costs if necessary.[71]

A question arises out of these criteria and guidelines: what happens to the person who meets all medically indicated need, and criteria, for being listed as a transplant recipient, but does not have sufficient social supports, available caregivers, or financial resources? The absence of psychosocial and financial resources likely results in the patient not being listed for a heart transplant, or at best being placed very low on the list (recall that only about half of those listed, and a third of those in need of solid organs, received transplants last year). On the one hand, if a transplant program, motivated by concerns for justice, seeks to transplant the patient most likely to have a successful outcome, and caregivers, financial, and other psychosocial resources are identified as crucial to good outcomes, then the decision not to list such a person is putatively in line with a view of justice.

I want to challenge this view. While it looks like an effective way to weed out less-likely-to-be-successful transplant patients, it does a disservice to those who lack a variety of supports and capital. Let's consider the issue of caregivers. We might think that people ought to have close, caring relationships in their life that would yield at least two people willing and able to provide the requisite care required of a transplant patient. Yet if we consider this requirement further, it relies on several embedded assumptions.

One is that people form and maintain deep interpersonal relationships that they can call upon for support. This might take the form of having a family member (parent, child, spouse, or sibling), or social network through friends and religious or other communities, to rely upon. It expects people to have cultivated these relationships in such a way that their caregivers are willing to commit to providing care that requires intense time, learning, and temporarily giving up other projects and activities. We might infer from this assumption that people who are valuable to others, with this value reflected in the willingness of others to care for them, are people more valuable in the world, and worthy of receiving a heart transplant.

But moreover, there is a further embedded assumption that expects that these caregivers, in addition to wanting or being willing to care for the patient, have their own resources that allow them to take the time from work or other caregiving duties (such as an adult child of the patient needing to both work a job and care for young children of their own) in order to supply this care.

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[71] Ibid.

There is a cascade of financial privilege that the psychosocial and financial criteria rest upon. These criteria require access to guaranteed health insurance, whether provided by the state or private insurance companies. They also expect patients to have additional resources to cover non-medical costs, including the cost of not working during transplantation and recovery, if one was previously employed. And if the patient's health insurance was provided through her own work-place health insurance program, then she will have to reckon with how to handle a situation in which she may no longer be able to work due to illness progression or the transplant process, but is reliant on her employer for her health care.

What happens when a patient does have family or friends willing to care for her, but are unable to, given their own financial constraints were they to take time away from a job in order to provide care? Or, more dire, what happens when a patient does not have deep, cultivated relationships with others who are willing to care for her? We might think that the patient has made her own choices to not make or sustain deep relationships of reciprocity and care. But I think this overidealizes the ways in which individuals make choices to engage and sustain relationships. As discussed in the second chapter, in Western society and Western medicine, a logic of choice prevails, but often masks the ways in which we have to grapple with the unchosen contingencies of our lives and world. We could imagine a person who, despite her best intentions to cultivate relationships that would result in care, with a spouse, or with children, perhaps, finds herself a widow and her children, for reasons of their own, unable to be caregivers.

Or we might imagine a person who is less sympathetic, one who has lived a history and cycle of trauma, or psychiatric disease, perhaps one who alienated friends and family, who is estranged from her own parents, who raised children in such a way that they have no love and affection for her, or who refused to commit to a spouse or partner. In the case of the unsympathetic figure, I want to suggest that we consider casting aside the logic of choice, to consider her case within a logic of care.

For people who have lived histories of trauma or abuse that challenge their very ability to form and sustain relationships, is this truly their choice to be without a viable caregiver now? For those families who have endured generations of poverty, is it their choice to not have the financial resources to devote to caregiving full-time, or to have access to sufficient resources to purchase professional care?[72]

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[72] Quite recently Nobel prize winning economist Joseph Stiglitz pointed out the ways that capitalism has failed those whose incomes and opportunities have stagnated, or are precarious, due to the structural

My suggestion is that we need to rethink these cases, and invite the possibility that in attempting to attend to justice, heart transplant criteria overlooks the twin injustices of blaming patients without interpersonal relationships of care, or financial resources, and unfairly advantaging those who have such social and financial capital in their lives. The reasons some have access to such resources, while others do not, may be reflective of historical, social, and structural features, beliefs, and practices outside the patient's control. We would need to seriously interrogate the systems, (cultural, social, financial, and political) that render some people better set up to cultivate interpersonal relationships and financial flourishing.

Even more seriously, we need to interrogate the real reasons (social, cultural, structural) that lead some folks to be less advantaged, and possibly recognize the histories of abuse, social exclusion and oppression, and inequities that render some folks worse off than others with regards to social and financial resources. We can recognize that women do a disproportionate amount of uncompensated care inside families, and that when they do work out of the home, they make less money than men in similar roles. There is also a growing recognition that identification into certain racial or ethnic groups influences health outcomes, regardless of socio-economic status.[73] We might therefore need to reassess our complicit participation in structural racism that produces and reinforces not only social oppression and injustice, but health oppression and injustice.

How could these structural inequities lead a female patient, for example, to be vulnerable if she has devoted her life to family care only to have a spouse leave her for another partner, rendering her without a dedicated caregiver, and without the same earning potential as if she had worked outside the home for many years? Is it just for her to be a lesser candidate for a heart transplant now? Does this reflect the justice of her own choices? Does it merely reflect the randomness of contingencies outside our own control? Or could we imagine practices that would not penalize a

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inequities and oppressive forces of capitalism, though this need not be the case. He claims that a progressive capitalism is possible that would reframe biased, exploitative and corrupt financial and social power structures. However, for the time being, these systems of oppression and exploitation of certain groups by other powerful groups, mainly those in elite positions of power within corporations, are the ones in which we live our lives in the US. See Stiglitz, Joseph E. "Progressive Capitalism is Not an Oxymoron" *New York Times* April 19, 2019 https://nyti.ms/2GpsQoQ.

[73] Jackson, Pamela Braboy, and David Williams. "The Intersection Of Race, Gender, And SES." In *Gender, Race, Class, And Health*, edited by Amy J. Schulz and Leith Mullings. San Francisco: Jossey-Bass, 2006, 131-162; Villarosa, Linda. "Why America's Black Mothers and Babies Are in a Life-or-Death Crisis: The Answer to the Disparity in Death Rates Has Everything to do With the Lived Experience of Being a Black Woman in America." *New York Times Magazine* April 11, 2018. Daniels notes that even when we adjust for differences of education, access to health insurance, and income, non-white Americans have worse overall health status than white Americans (Daniels, *Just Health,* 14).

person for her social and economic conditions with regards to her health care, by instead recognizing that they are a mix of chosen and unchosen circumstances, influenced heavily by history, custom, and given practices internal to her community?

We ought to analyze these cases with an eye toward an expanded concept of health care, that extends social, financial, and possibly political resources as an integral part of care. Rather than simply removing people from a pool of potential care recipients, as is the case when certain psychosocial criteria are used to exclude patients from the heart transplant list, we may need to think creatively about revising these practices and policies to either modify this criteria, or, given the criteria's importance for successful transplantation, identify ways to provide requisite social and financial care and support. Such extension of financial and social support, in conjunction with reconceptualizing care itself and who has obligations to care, would bring heart transplant criteria into a more just practice. In the next chapter, after arguing for the kind of ethical community that, informed by a complicity framework, ought to take responsibility for care and care justice, I will return to this suggestion.

One might interject that there is still a problem of how to deal with real limitations on goods and scarcity of resources. Some tool needs to be used to allocate a limited resource, so why not adopt a tool designed to yield the highest return on the scarce goods? I agree that we should best use all resources, whether they are scare or not, since most resources are in some ways limited and costly (whether that be in terms of money, time, environmental impact, or social impact). Health care is rife with limited resources: goods, services, personnel, hospital beds, dollars, etc.

When it comes specifically to the practice of medicine, medical criteria need to drive medical determinations and the appropriateness of medical care. But recall that medicine is a normative practice, and evolving values and practices within medicine and society at large move the needle regarding medical norms. We saw this in the first chapter regarding approaches to disability and prognosis for infants born with conditions that were previously deemed incompatible with life, but have since evolved to be recognized as life-limiting, though not necessarily life-incompatible. This shift occurred because medical practices changed, both in terms of technologies available and the values surrounding the application of these technologies. These changes resulted in medically treating these infants in ways that can in fact extend their lives.

My point is not to abandon necessary criteria as setting the standard for the allocation of donor hearts to appropriate recipients. For now, until or unless technology can develop non-human hearts that can replace failing human hearts, or medicine is able to reverse heart failure before a replacement heart is necessary, we will continue to have more people who need hearts than there are hearts available. I do not have a solution for the lack of resources, I merely aim to show that the current allocation scheme of these resources might not do the justice it intends to.

As argued in the second chapter, I advocate for health care to encompass more than mere medical care, and there may be non-medical features that can and ought to be provided to individuals to meet their health aspirations, some medical needs, and the justice owed to them through care. In practice, what this could look like is a reorientation of psychosocial criteria when making medical decisions. We can retain medical criteria, but need to recognize that the provision of psychosocial goods might need to be part of the package of medical care (that is to say, part of a broader notion and package of health care), not a prerequisite to receiving care. Regarding heart transplantation criteria: it is possible for a person to meet all the "medical indications" save the social and financial components. This situation spells out that there is currently a distinction between medical and non-medical component to a health care procedure.

An expanded definition of health care supports a shift away from rejecting otherwise medically qualified individuals from a resource or procedure in light of their psycho-social circumstances. It instead embraces these features as part of their relevant health care. Yes, there will still be limits. But things like stable housing, having an available caretaker, or treatment for drug or alcohol dependency, could all be part of, not required prior to, accessing medical treatment.

What this means is that patients can continue to be listed in the order of need, based on severity of their heart failure, and likelihood of transplant success. But instead of ruling some people out for a lack of psychosocial support, that makes them less viable candidates, they are supported to be made eligible for transplant, with psychosocial supports in place so that would foster a successful transplant were they to receive a heart. This might simply lead to many more people who are technically eligible for transplant, and even more people listed than there are hearts available. We can continue to prioritize listing, and listing order, based on medical features of a patient's situation.

By maintain psychosocial criteria, but removing some constraints in accessing that criteria that might be unjust, we would create more equitable conditions for individuals to have at least a chance of a transplant if they are most in need, recognizing that unfortunately many people will still be left without access to a much-needed donor heart. Hopefully they are not left out merely because they don't have adequate financial savings, or close caregiver relationships in their life. In the next chapter I map out my program for what kind of moral community can support such an approach, and return to this case of heart transplant criteria to propose a new way forward.

VI

Complicit Ethical Homes

In this chapter I offer my view of a moral community as an "ethical home." I clarify what kind of home I am talking about, and why "home" is a useful concept for the kind of moral community that I argue is both the source of, and responsible for, the rights of those who share in an ethical home. Ethical homes are created through complicit participation in the practice of home-making. A valuable feature of my view of complicity, as argued in the previous chapter, is that it not only affords a tool for attributing accountability for harms, but it also establishes a framework for establishing responsibility to address harms.

A complicity framework motivates the view of moral community as an ethical home. Complicity coheres and defines ethical communities in which we have rights and responsibilities. Because, I argue, we complicitly form the moral community, we are responsible for its practices, including the rights valued and recognized by the moral community. At the same time, due to our complicit participation in forming and upholding the community's practices, we are obligated to protect, respect, and fulfill the rights valued and endorsed within the ethical home. The fact that we are complicit in each other's pasts and presents make us also responsible for each other's futures.

As an extension of this view, I suggest several of its implications for health care policy and practice. I briefly consider four main objections to the view, to which I reply. I typify these four concerns as: the worry about care everywhere; the love and affection concern; the problem of institutional warrant; and the worry about material goods.

Then I return to the example of heart transplant recipient listing criteria, which I began to illustrate in the previous chapter. By returning to and elaborating on this example, I show how an ethical home would require modifications to either transplant listing criteria, or the social practices relevant to the criteria, in order to bring heart transplant listing criteria in line with the kind of care justice I argue ought to be present in complicit, ethical homes.

This is only one possible example of how ethical homes are able to practice care justice, but its contours suggest the kinds of attention, representation, and affiliation that ethical homes afford, and that can enact health care justice, grounded in the value and practice of care.

Moral Community, Complicity, and Ethical Homes

In this section I establish three points: complicity is a useful way to frame individual responsibility within a collective; complicity is a tool to understand moral communities as "ethical homes;" and the responsibility generated by complicity yields both accountability for harms, and obligation to produce positive effects. My objective is to show that "ethical homes" create a kind of community that is more flexible than communities produced through traditional conceptions of membership from which rights usually follow. Relatedly, I aim to show that "ethical homes" are a more engaged way for individuals to be accountable to others with whom they share an ethical home, including responsibility to fulfill the rights that flow from this kind of moral community.

Importantly, the kind of complicity in ethical homes for which I argue makes sense of how complicity can respond to the phenomenon that some goods are brought about only via collective action, i.e. cannot be achieved by an individual alone, yet also require individuals to take part, and do their part, in a group project. This occurs through three premises. First, participation in ethical home-making is participation in the moral self-definition of a community. Second, building on Walker's justification for moral particularity, this practice of moral self-definition is the intentional participation in the formation of practices that both cohere and define a specific moral community that is the ethical home.

Third, participation in and formation of the practices of the ethical home that render an individual a member in the ethical home are also what render her complicit in it. Because complicity on my view is two-sided, it is an attribution of accountability for existing or prior conditions. But it is also the imposition of responsibility for forward-looking obligations, in light of backward-looking attribution of responsibility. Therefore, being complicit is being responsible for past actions and practices, while also taking responsibility for addressing the results of such practices, and when necessary, modifying them.

Starting with my first premise: participation in ethical home-making occurs through the moral self-definition of a community. In prior chapters I rejected rights frameworks that I described as requiring the possession of a certain status (as human, or as citizen). I have equated these rights practices as treating rights as things that we own, like we possess property, such as a house. Instead, of viewing rights as having ownership or control over goods (or status), I turn the focus to the process of relating to others, and to the process of making rights in relation to others. In contrast to the idea of houses, which are owned, I describe this relational and process-based account as a "home."

I primarily use "home" as a conceptual framework, and not as a literal account of what makes a particular physical space, such as the structure of a house, into a home in the way that comes to mind when we use a phrase to say some particular feature (often the presence of family or loved-ones) is what "makes a house a home." I do not attempt to define home through analogy, as we saw done with health in the first chapter, and which revisit with the analogy of personal commitment later in this chapter. I am not importing conventional notions of hominess onto the moral community. My point is not to convert literal, or for that matter even conceptual, houses into homes; instead my aim is to suggest that particular conceptual features of home are useful for thinking about what constitutes an ethical moral community.

Here I need to acknowledge a fraught history for the concept of home. Young has pointed to a tension in feminist scholarship regarding the concepts of houses and homes. She notes that home can be confining, particularly for women, who have historically been the designated homemakers tasked with being subservient to men, and catering to the needs of men and children.[1]

Yet she adds that home can also be a liberating idea because it is an expression of uniquely human values, and a space in which one can explore and express her own unique identity.[2] Taking a literal view of houses and homes, Young suggests that possessing a house as a commodity does not function in a self-expressive way, whereas "a home, on the other hand, is personal in a visible, spatial sense… the home displays the things among which a person lives, that support his or her life activities and reflect in matter the events and values in his or her life."[3]

While I read Young to be describing a home as a house or structure that we fill with certain "things" and these things are likely objects, they are not necessarily material objects, nor do they necessarily have monetary value. They could be photographs, mementos, or items that facilitate a comfortable life such as a favorite blanket or reading chair. This is a different relationship to goods than as mere commodities: it describes relating to those items, which have both practical and emotional meaning, to enable and enact the life that reflects and promotes one's values.

As Young goes on to say: "the home is not simply the things, but their arrangement in space in a way that supports the body habits and routines of those who dwell there."[4] In other words, a home for Young is also the established practices, customs, or habits of relating to the things (and

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[1] Young, Iris Marion. "House and Home" in *On Female Body Experience: "Throwing Like a Girl" and Other Essays*. New York: Oxford University Press, 2005, 123.
[2] Ibid., 124.
[3] Ibid., 139.
[4] Ibid.

presumably other living entities) that exist in the home. Again, I take this account to remain too literal, but find Young's distinction between house and home, and also her deftness at working through a "deep distrust of the idea of home for feminist politics" that would suggest feminism ought to reject the concept of home outright, helpful for identifying features of the concept of home that nonetheless remain fruitful sites of inquiry.[5]

On Young's account, home is not about "longing for comfort and unity," but instead about leveraging home "for radical social critique" as a "site of dignity and resistance."[6] Young adopts and develops bell hooks's political vision of home. hooks describes home as: a space that is safe; where you will not be hurt; and where wounds can heal.[7] Young suggests that a "positive idea of home… is attached to a particular locale as an extension and expression of bodily routines" and that home as a critical value includes four normative values: safety, individuation, privacy and preservation.[8] She claims that "to the extent that having a home is currently a privilege… the values of home should be democratized rather than rejected."[9]

Furthermore, connecting home to nationalism and a "homeland" is the wrong model for a home – a point on which I strongly agree with Young. She indicates that a nationalist model of home creates and perpetuates distinctions (namely, between us and them, or citizen and non-citizen), projects the idea of home across too great a space if it needs to encompass an entire territory (this would be particularly true of a large territory such as the United States), and suppresses, rather than recognizes, differences within and among a whole.[10]

Connecting a home to a concept of homeland is to reinforce logics of citizenship, state membership, and possession of status. On my view, national identities are better described as reflecting a relationship to a "house-land" rather than a "home-land." To engage the term "home" for a national identity is to misunderstand and misuse the concept of home. Indeed, citizenship or state-based rights and recognition does uphold logics of us and them, though any system of membership will necessarily need to include and exclude. I agree with Young that appealing to nationalism potentially encompasses too large a space and too many members. To me, this prohibits it from being effective in drawing out individual responsibility for collective acts or omissions, while

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[5] Ibid., 146.
[6] Ibid.
[7] hooks, bell. *Belonging: A Culture of Place.* New York: Routledge, 2008.
[8] Young, "House and Home," 150, 151-153.
[9] Ibid., 146.
[10] Ibid., 150. This third point is also a feature of Young's critiques of political liberalism.

also not supporting sufficient cohesion to produce strong commitment to fellow members. My account of home favors the notion that the process of making a moral-home is the process of moral self-definition of a particular community, and this is what renders it a moral community in which its rules and rights are created, protected, and fulfilled.

Finally, in assessing Young's account, I am hesitant to endorse that home is strictly a privilege. While having a traditional sense of home is a privilege, I am arguing that having a conceptual home is a feature of how we organize our moral communities, rather than a privileged status within them. Part of what is at stake in recognizing that there are others with whom we are already in a relationship of "home" is to recognize that there are instances in which they do not have access to the privileged features of a traditional home, and that as a matter of justice, certain of these features must be redistributed or democratized within ethical communities. That is to say, rather than rejecting home on the grounds of historical inequities of privilege, the thought is to extend home as a way to redress these inequities. In this manner, home does, as hooks says, become a place to heal wounds, including historical ones.

What do I mean by this? My point is not that any single "home" or even model of "home" should be extended to all. Instead I am suggesting that we recognize that the homes we make have a wider reach than other kinds of communities in which we engage (that tend to be bounded by features such as shared kinship, race, religion, nationality, socio-economic status, language, or even those we think of in our literal homes with whom we often share blood or legal kinship).

The value in calling a moral community a "home" is that it connotes a process of making, rather than merely a physical place, though it can be that as well. It may be that a home grafts on to a geographical area in which a collection of people lives in interdependence with one another, and establishes customs and practices that support their daily life, bodily habits (or needs), values, and routines. Yet this space of the "home" may not subscribe to the neat boundaries provided by municipalities, congressional districts, or legal borders.

By understanding moral communities as ethical homes, we embrace the notion that we make, remake, and, if necessary, can unmake homes. The practice of home-making is an iterative and alive one, that attends to history, but also projects into the future. The notion of "commitment" might follow from this, but it is not the only condition for ethical homes, since our homes might also reflect our thrown circumstances to which we haven't initially committed, but with which we may still need to contend. And there remains a risk that our thrown circumstances lead to oppressive homes.

This risk is real. Yet this is why there is the open possibility of remaking and unmaking a home. In a sense, because we are committed to a home, we are also committed to do this work of remaking. Though we also remain open to unmaking the home, if this is the only option to avoid further harm or injustice. To unmake a home would then invite the making of a new one. This view of moral community as ethical home better captures our lived experiences. It is not an ideal structure that imagines an end to oppression or inequity, but instead imagines a mechanism for attending to the real and ever-present possibility of both. This account works from an assumption of historical oppression and inequity, and attempts to hold the ethical home together in light of, and accountable for, complicity in such historical injustices.

Turning to my second premise: moral self-definition within an ethical home is the intentional definition (or redefinition, when necessary) of the moral community. This second premise underscores the role of intentionality within ethical home-making. As noted in the previous chapter, this addresses a frequent stumbling block for accountability: the problem of intention.[11] There is a puzzle within collective action and political theory about how individuals come to be bound to the group (normally the state) in which they find themselves.

This is particularly true of democratic theory in which individuals impose limits on themselves to be bound to a government with the coercive power over them, of which they are also the authors. Solutions often take the form of programs of hypothetical or tacit consent, or a program of non-dissent, such as Socrates's assertion to Crito that he consented to being a citizen of Athens by not exiting the state when he could have.[12] David Hume takes consent even for the initial "infancy" of a government to be more aptly described as a "voluntary acquiescence of the people," despite the promotion in political philosophy of a notion of an original consensual social contract.[13]

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[11] While I am talking about intention at the level mainly of collective engagement, this is no less a problem for individual attributions of accountability. For example, David Shoemaker has considered how in fact there are three different features that contribute to individual responsibility: attributability, accountability, and answerability, with the idea that levels of intention, voluntariness, and control factor differently into each of these dimensions. See Shoemaker, David. *Responsibility from the Margins.* New York: Oxford University Press, 2015.

[12] Estlund, David. "Political Authority and the Tyranny of Non-Consent." *Philosophical Issues* 15 (2005): 351-367; Estlund, David. *Democratic Authority: A Philosophical Framework.* Princeton: Princeton University Press, 2009; Edmundson, William A. "Consent and Its Cousins." *Ethics* 121.2 (2011): 335-353; Owens, David. "The Possibility of Consent." *Ratio* 24.4 (2011): 402-421.
Plato. "Crito" in *Five Dialogues* translated by G.M.A. Grube. Indianapolis: Hackett Publishing, 1981.

[13] Hume, David. "Of the Original Contract." *Essays – Moral, Political and Literary.* Indianapolis: Liberty Classics, 1987.

Furthermore, any original consent, should it have been truly voluntary, and not through some degree of persuasion, coercion, or force, still encounters a problem for durable authority over future generations, who did not directly consent. Such a model supposes "the consent of the fathers" is able to "bind the children, even to the most remote generations,"[14] which looks like yet another form of coerced, or at best acquiesced, consent. This is to say that when states are the primary agents for the granting of rights and the fulfillment of responsibilities to those rights, individual citizens (let alone those excluded from citizenship) might have a less that fully voluntary or intentional role as participants.

To some extent Socrates counters the inherited and unchosen history of citizenship by claiming that the choice to remain is the relevant expression of choice – this is the demonstration of intent to be a citizen bound by the state's laws and responsibilities. But freedom of movement, whether to exit an oppressive state or to enter into a chosen state, is restricted in such ways that it would be incoherent to claim individuals are expressing an intentional choice by remaining in their nation-state of birth in the contemporary moment.

Hume suggests that the idea of initial consent to a social contract misconstrues the scope of individual choices, particularly within structures of inequality.[15] This recalls Annemarie Mol's distinction between a logic of choice and a logic of care, and feminist critiques of choice more broadly, that reckoned with the ways in which many of our circumstances are outside of our control, or are ones into which we are always already thrown.

Understanding moral communities as different from institutions like states, and as being reflected through intentional participation in a community's practices, can make sense of the problem of initial consent to participate in a collective. This approach also makes sense of our thrownness into circumstances outside our own initial choosing. We may not choose the original circumstances that render us participants in a particular moral community, but nonetheless we take responsibility for the practices, and our fellow members, in the moral community in which we are intentionally presently engaging. My claim is an updated take on Socrates's own persuade or obey argument from *Crito*, with a different take on obedience.

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[14] Ibid.

[15] His critique of the structural inequalities that are masked by appeals to supposed natural equality of all of mankind foreshadows the more explicit critiques of equality and social contract that arise in contemporary analyses of contract theory including those of Iris Marion Young, Carole Pateman and Charles Mills, all of whom take aim at the intersection of difference and injustice with regards to egalitarian and liberal ideals of social contracts. See Pateman, Carole and Charles Mills. *Contract and Domination.* Cambridge: Polity Press, 2007; Young, Iris Marion. *Justice and the Politics of Difference.* Princeton: Princeton University Press, 1990.

In my formulation, obedience is replaced with complicity, such that community members are not meant to obey the coercive power of laws or rule, but are to take complicit responsibility for those laws (which may take the form of practices, rules, customs or policies) which their participation in the moral community generates and enforces. This is a different mechanism for self-binding to a social contract, in which the social contract arises out of participation in the practices themselves. Being part of an ethical home is in many ways apart from any logic of choice: it is inherited, received; usually it occurs in the place in which we find ourselves. Yet we nonetheless make choices within the unchosen, and these choices indicate some intentional participation in interdependent practices with and among others.

Part of what I already noted is valuable about the concept of home is that it is a process that requires making and remaking, instead of passive acceptance or receipt. Socrates's tenet to persuade the society to amend its laws is one type of remaking that may not only be an option open to us as ethical home-dwellers, but also one that is at times required of us. My point is not to merely persuade or obey the moral community in which one finds herself, but to actively create and recreate it in a way that conforms to one's individual moral self-definition, and the moral self-definition of the community in which one is a member.

This requires us to recognize prior failures within our moral community. Because such failures are a reflection of our own self-definition and interdependence within an ethical home, we are complicit in them in a backward-looking sense. Yet we are also complicitly responsible for them in a forward-looking sense. We must take the necessary steps to modify and amend failing practices. Importantly, our complicity in the practices make us obligated to do so, even if they are not practices which appear to directly impact our own lives. As participants in the moral community, its members receive rights, uphold rights, and have responsibilities to persuade the moral community to reform its practices when they are no longer appropriate, or are revealed to be unjust or insufficient.

This leads to my third premise, that the participation in and formation of the practices of the ethical home that render an individual a member in the ethical home are also what render her complicit in it. By being thus complicit in the formation and perpetuation of the moral community, that is to say, the ethical home, individuals are complicit in the practices of the community regardless of whether they would meet the criteria for complicity in each particular act (or omission) of the moral community.[16] To be complicit in such practices entails obligations to reform practices that

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[16] Though sometimes I specify both acts and omissions and elsewhere speak just about "acts," I intend acts and omissions; in many of the particular instances I have in mind related to the provision of health care,

result in unjust, oppressive, exclusionary or unfair practices, and to endorse and support those practices that produce just, appropriately inclusive, and fair acts. Fairness on this account arises not out of strict equality, but out of an equity that is sensitive to particular features of vulnerability, need, history, structures, and capacity. We might say, following Walker, as I did in the prior chapter, that it is about equity of attention to each person, acknowledging that when we attune our attention to each person and her needs, we will likely arrive at a distribution of other goods (including attention) that does not follow a program of formal equality.

In the second chapter I argued that care itself is a practice and value that contributes to and expresses what I now am further developing as the moral self-definition of an ethical home. That is to say that how we care, what we care about, for whom we care, and what is recognized as appropriate care are all components of the morally-self-defining features of a community, or an ethical home.

For example, we recognize health care as a valuable feature of our moral community in the US. However, as previously argued, apt health care requires a conceptual expansion of what is included under the umbrella of "health care." In addition, I am now suggesting that who we must care for as recipients of this expanded notion of health care is also likely broader than we think. In my ethical home model, all of those with whom we share in our ethical home, that is to say, our moral community, are both holders of rights to health care, and obligated to fulfill responsibilities of health care (with health care indicating a package of medical, but also when necessary social, economic or political goods).[17]

Because the moral community values care, and has self-defined in part through this value and practice, it becomes an intentional and defining feature of an ethical home. Care is not the only value or practice that has this cohesive, morally defining quality within ethical homes, but it is a key value and practice that produces such a result. Following my third premise, I will argue that it is the moral community thus defined that is the grantor and protector of rights to care. In this way, care is

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responsibility for omissions are of central concern: they are failures to care, or they related to a perceived non-responsibility to care for others. My hope it to show that, along with those who have come before me in the shared responsibility and moral entanglements literatures, we often do have much more significant obligations to others than those of which we might be on the surface be aware, and that these duties are entailed by the rights claims of others, not mere charity.

[17] Though my point throughout is that ethical homes can, and often should, be quite specifically delineated communities. There may be layers of moral communities that extend globally, for example, but ideally these will be in conjunction with more narrow ethical homes, that reflect a limited and cohesive moral community as well.

effectively an alternate route for individuals to have rights that follow from the practices and values recognized by the ethical home community, and also a mechanism for individuals to take responsibility for protecting the rights of others with whom they share an ethical home.

Ethical homes can better protect right for two key reasons related to the complicity of ethical homes. One, they implicate fellow home-members directly in the establishment and endorsement of which rights are valuable and enforced in a given community. This direct implication makes individuals, not only the group (such as the state) obligated to attend to the protection, respect, and fulfillment of rights.

Effectively, this means that each member of the ethical home has a claim on the other members to respect and protect her rights. Because I am interested in rights such as a right to health care functioning as a claim-right, this means that within ethical homes claim-rights entail duties on fellow home members. While this does not always or even often mean a direct one-to-one correlation that one member of the ethical home directly imposes duties on me to fulfil her particular rights, I do take this to mean that she has claims on me to take relevant actions to protect and respect her rights when they are not being fulfilled, including actions to reform relevant institutions that can fulfil these rights.

Secondly, ethical homes do a better job of including those who are otherwise excluded from traditional models of rights and membership, such as through states. Again, this relies on the way complicity functions in the ethical home. When ethical home members recognize their complicity in establishing or allowing oppressive systems, or exclusionary systems, including historical structures that lead certain members to be unfairly disadvantaged (due to race, gender, sexual identity, ethnicity, religion, etc.) or certain members to not be recognized as members at all (such as the migrant who coexists as a participatory member in an ethical home, though without the recognition of traditional institutions such as the state), then ethical homes have greater plasticity to, and are in fact required to, revise rights practices to be more just, appropriately inclusive, and rectify unjust exclusions.

The route to membership through intentional and active participation in the practices that form and cohere a moral community avoids traditional identity-based markers for inclusion or exclusion in the moral community and its formative institutions. Although "ethical homes" still reflect and create a sense of identity. As Kwame Anthony Appiah has argued: "identities make ethical claims."[18] We have claims as certain identities (as a woman, as a disabled person, as a child or parent, as a citizen, as an asylum seeker).

Yet recalling Wendy Brown's astute observation, rights packaged with identities bring a paradox of rights claims that ride on the very identities that oppress. Having rights as a woman, she argues, grants rights while continuing to reinforce my participation in a subordinated group.[19] Identity-based membership includes some by necessarily excluding others. This is an obvious feature of all forms of membership, but is worth drawing out because it risks creating inclusions and exclusions based on unjust practices such as racial or ethnic discrimination that might otherwise go overlooked as merely reflecting "identity markers," and not historical oppression; furthermore, they may then reinforce such oppression in the present.

Identifying across some markers seems to yield worrisome results. Relationships matter, and how we relate matters, but Christopher Wellman has challenged what kinds of relationships should generate particular duties. He says there is not magic in the pronoun "my," because "it is absurd to posit special duties to all relations."[20] He notes that we would not think we have special duties toward "my" enemy merely because we use the relational pronoun to indicate their status as enemy.

Like Young's critiques about associating home with country, Wellman critiques associating duties with country. He points to how this approach could also be (problematically) extended to other groupings to which one belongs such as race, gender, religion. It starts to look discriminatory, not merely delimiting, when we show preference for those who belong to "my" group in certain ways.[21] Relations are important, but need to tell a story about the nature of those relationships. This is the story I am telling about the self-definition of a moral community as an ethical home.

This story is different from one that is primarily descriptive about the community or circumstances in which I find myself. It is one thing to know, observe, or name the features of the moral community into which one finds herself thrown. This reflects the kind of collective identity Appiah says "we might call scripts: narratives that people can use in shaping their projects and in telling their life stories."[22] Yet he further notes that a shared history is insufficient for generating

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[18] Appiah, Kwame Anthony. *The Ethics of Identity*. Princeton: Princeton University Press, 2007*,* xiv.

[19] Brown, "Suffering Rights as Paradoxes," 232.

[20] Wellman, Christopher Heath. "Relational facts in liberal political theory: Is There Magic in the Pronoun 'My'?" *Ethics* 110 (2000): 537–562, 552.

[21] Ibid., 553.

[22] Appiah, 22.

group membership "for we need something by which to identify the group in order to identify its history; and that something cannot, on the pain of circularity, be the history of the group."[23]

What I am arguing is that morally self-defining through practices provides the extra step that moves individuals and collectives from the shared history of circumstances of time and place (merely finding each other in a particular moment and geographical or socio-political setting) and into a set of co-constructed and intentional practices. Moral self-definition provides the additional layer of cohering the group together as a collection of individuals contributing to the project of moral self-definition and community formation through the practices and values they enact, create, resist, and reinforce. This is the process of ethical home-making.

Furthermore, ethical home-making does not rely on, though it acknowledges, shared history, readily apparent shared identity markers, or other contingent features of our world. These include the features we understand to be quasi-participatory about our world, and the features that lead Marin to find Kutz's account of complicity insufficient to generate the kinds of claims she thinks we need to generate. Samuel Scheffler suggests that identity itself generates claims, and that often this identity is unchosen: others claim us as belonging to a nation, a clan, or a family: "from the moment of our birth and sometimes sooner, claims are made on us and for us and to us. We are claimed by families and clans, by nations and states, by races and religions, by cultures and communities and classes - all clambering to confer privileges and responsibilities up on us."[24]

Wellman accepts the descriptive point that "we are in fact more likely to help those with whom we identify," even if this is not a moral conclusion that duties rely on such motivations.[25] If this observation is worrisome to us, as I think it should be, it might lead us to rethink what it is to identify with, and who we leave out when we identify too narrowly with only those who share readily legible "like" features to us.

When we acknowledge given interdependence as individuals within a moral community of our own collective making and self-definition, we may need to radically expand out the notion of with whom we share in our ethical homes. This is the work of ethical home-making as a practice itself. And it is through ethical home-making that membership in our ethical homes is not merely

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[23] Ibid., 136-137.

[24] Scheffler, Samuel. *Boundaries and Allegiances: Problems of Justice and Responsibility in Liberal Thought.* New York: Oxford University Press, 2011, 64.

[25] Wellman, 558.

quasi-participatory, but instead truly participatory. This participation can produce something stronger than commitment: it can produce complicity.

To return to the third premise: participation in and formation of the practices of the ethical home that render an individual a member in the ethical home are also what render her complicit in it. Out of this premise I generate two additional claims. One, not only does complicity cohere a moral community, but it is also this moral community as ethical home that generates rights to the values practiced within the ethical home community, rights held by each member of the ethical home. And two, each member of the ethical home is responsible for protecting the rights of her fellow members. This second additional claim is particularly crucial to my account of shared responsibility, and why I engage a framework of complicity to generate this strong obligation.

To be clear, I do not mean to say that each individual is in a one-to-one relationship to every other community member with a direct obligation to fulfill her rights. However, it might render each individual directly responsible for protecting and respecting individual rights by contributing to conditions that would fulfill others' rights. When such conditions are not met, then it is additionally the responsibility of fellow ethical home members to engage in steps necessary to revise the practices of the ethical home in order to bring them in line with practices that can protect, respect, and fulfill the rights held by all members.

Scheffler observes that when a group is implicated, we tend to see our individual participation in the effects of the group as less impactful than when we are the sole agent of an effect.[26] He adds that the ways in which apparent individual choices are in fact institutionally structured, as well as the impacts and effects of such choices, might not be readily apparent to an agent, which Scheffler claims can lead to "doubts about our practice of treating the individual agent as the primary locus of such responsibility."[27]

This seems right, but it does not address another category of cases: those in which, because of institutional structures and the guise of individual choice, we fail to understand how groups are implicated in what we otherwise take to be situations of individual responsibility. One place where the care theory and partiality theory converge is around the unchosen nature of many of our circumstances. Scheffler notes that "to the extent that we choose our roles and relations, and decide

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[26] Scheffler, 39.
[27] Ibid., 44.

how much significance they shall have in our lives, we share our own identities. But to the extent that these things are fixed independently of our choices, our identities are beyond our control."[28]

Mol's analysis of the logic of choice suggests that we overemphasize individual choices and under-acknowledge contingent circumstances and dependence. There is a balance between what is chosen and unchosen: the facts of our birth, or geography, the histories that came before us, our reliance on both proximate and distant others, all feature into something non-voluntary about our existence. These should compel us to recognize limits to any purported logic of choice.

However, returning to my previous claims regarding care, what happens if we recognize that care is not merely about personal commitment to recognized relationships that we think we have more overt control in choosing? I am suggesting that care is a value and practice that coheres a moral community – one that defines the boundaries of an ethical home, and also extends rights, including a right of care, to those who participate in it. In doing so, I am further suggesting that instead of treating care, or its absence, as arising out of a set of individual, personal choices and relationships, including the choice to engage in relationships that would yield special duties (such as parenthood or romantic partnership), we need to recognize care as part of a collective obligation. But by using a complicity framework to think about how we individually participate in a collective, for which we have shared responsibility, we can retain the role of individuals as agents responsible within the group, rather than dilute individual responsibility to collective or group action.

Individual accountability to fellow moral community members is more than merely finding ourselves thrown into particular circumstances (though to an extent we are). It is the additional step of taking and being responsible for those circumstances, in both backward and forward-looking notions of responsibility. Once we recognize that we are complicit in the practices and values expressed and reflected in our moral community we have to take backward-looking responsibility for the conditions which we have brought about, or permitted to perpetuate. This implication, often in the form of blameworthiness for historical harms (exclusions, oppression, structural injustice, inequity), is also an implication in the forward-looking project of reforming the practices and modifying the values that allowed harms to occur.

Describing complicity as backward and forward looking reflects what I have already described as the two sides of complicity: not only am I blameworthy for my individual contribution to the collective harms, but I am individually responsible for contributing to the rectification of such

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[28] Ibid., 105.

harms. A complicity framework places greater emphasis on individual roles in bringing about social change and justice than we tend to ascribe to individuals. This is especially true for harms that are the product of systems, institutional practice, and which primarily (if not only) occur through aggregate action. We tend to think of these as requiring collective, widespread social change and reform. And widespread change is necessary. But my objective, however, is to better understand how individuals are nonetheless accountable for this change, and cannot deflect responsibility onto institutions or occasional and small acts of engagement, such as voting in political elections or ad hoc acts of charity.

A complicity framework is a way to understand how individuals are engaged in and producers of these very institutions we deem the apt targets of responsibility. Complicity is about understanding the individual role within a collective, not apart from one. It would be insufficient for a single individual to take sole responsibility, even if she could.[29] The point is to understand a dynamic relationship between individuals and their responsibilities within and to the moral community that they form and participate in together. This occurs first by being complicit in the community itself, which shapes and coheres the moral community.

Then, as a second step, individuals complicit in the community are then complicit in the actions and omissions of this moral community. Marin seeks to justify "obligations to transform oppressive structures" without an appeal to a natural theory of justice, or to an account of complicity, and favors the concept of "commitment" to generate "individual responsibility for injustice" along similar lines to the "obligations of personal commitment."[30] However, I don't think this makes sense of why we are obligated to commit to reforming institutions and structures, particularly those structures or institutions that might be unjust toward others for whom we ought to care, and not merely unjust toward us.

Marin holds that analogizing social structures with personal relationships is helpful to make "unfamiliar ideas familiar,"[31] yet it also imports possibly problematic normative assumptions along with helpful familiar ones. For example, Marin takes personal commitment to require mutuality and

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[29] So the thought here is that even if I had the kind of money someone like Jeff Bezos has, the point would not be for me to singlehandedly act to bring about the kinds of changes that I think would produce right outcomes (access to care, social and economic goods, etc.), although this might be a good thing. The point is to support a community to engage together – it is the doing together that is important because the community creates, supports and enforces values and practices that reflect it and in which its members participate together.

[30] Marin, 11.

[31] Ibid., 61.

reciprocity because, on her view, relationships cannot be one-sided.[32] Yet this needs to be qualified. Relationships cannot be individual; by definition they are placing at least two things in relation to each other. But they can be imbalanced. And cases of imbalance might be the ones that most require us to act with and for others. A worry is that commitment expects too much of individuals to do the right thing by recognizing needs. And then it further expects too much of individuals to enact justice, and to change or reform that which would be required to change or reform in light of justice demands, out of a commitment – but not obligation – to others.

At the same time, it does not generate an effective mechanism for those negatively impacted by the very structures of oppression we are supposed to commit to overturning to demand this change, or make a claim on those in power to engage in reform. The structure of personal commitments is not sufficiently akin to strong obligations on the part of the person committing. When we personally commit, we are making an individual pledge. However, whether others can hold us accountable for this individual pledge is debatable. Marin takes commitment to require follow through and action, such that there is an external product of our commitment. Yet Margaret Gilbert points out that the person committing is the "sole author of a commitment and has the authority to unilaterally rescind it."[33] Some commitments are joint commitments (commitments to contracts, including a marriage contract, are intended to be mutual) in the way Marin imagines. However other personal commitments are individual and internal, as Gilbert claims (think of the many New Year's resolutions people pledge, and then sometime in January rescind).

Personal commitments do not always generate the intuitive familiar cases Marin thinks they do. For Gilbert personal commitments remain unilaterally endorsed or retracted, whereas Marin takes commitment to mean a mutual structure. Even if commitment rests on a mutual structure, then we might wonder who is left out of commitments because they are unable to make or commit to obligations.[34] Marin claims that in the social sphere we are "mutually responsible to undermine oppressive structures" by virtue of commitments. We would need a further account of what creates and sustains conditions of mutuality.

Where commitments come up short, complicity offers a framework for a kind of co-engagement that recognizes and even expects power to be uneven. Those situated in positions of

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[32] Ibid., 36.

[33] Gilbert, *Sociality and Responsibility*, 21.

[34] This recalls the discussion in chapter two of "co-engagement" as preferable to reciprocity or mutuality in order to make sense of imbalances in ability to reciprocate in some relationships in which one is nonetheless demonstrating engagement.

relative power in a social structure, in light of being complicit in the systems that have created this imbalance of power, arguably have greater responsibility for those who have been historically harmed by complicit community or who are continually at risk of harm through the practices of the community that require reform.

In arguing that complicity hold together a moral community, I mean by moral community a collection of individuals who are, as Kathryn Paxton George has said, "the objects or subjects of moral concern or both," and in the moral community we recognize the community members to have "a good of their own that we recognize as making some claim upon us to practice restraint or to exercise active intervention on their behalf."[35] Being complicit in a moral community is what make us rights holders. The rights themselves arise out of the values and practices created and endorsed by the moral community in an ethical home.

And as complicit members of the ethical home, we have moral standing in the community. We have standing in the moral community by being makers of the ethical home, and are recognized as having this standing through a process of co-engagement. And because we have standing, we are recognized as having rights that the ethical home and our fellow members in it are obligated to protect, respect, and fulfill.

Additionally, as complicit members of an ethical home, we are responsible for the rights of others who also have standing in the moral community, and for whom we have obligations on their behalf. It is inside complicit moral communities, ethical homes, that our rights originate, and are also realized. These include a right to health care, which might epitomize features of the social and home-based nature of rights and responsibilities, because as I have already argued, health care is a social enterprise built around the value and justice of care, or care justice.

In previous chapters I considered examples of undocumented immigrants in the US who were excluded from necessary medical care because they are not recognized by the state. Certainly individual citizens in the US could charitably contribute to organizations that support undocumented migrant health care, or even directly sponsor the health care of a particular person or family if they were aware of their situation, and in a financial position to offer aid. This would be viewed as generous, and supererogatory action on the part of such individuals. Yet health care should not fall under the category of the supererogatory. Health care ought to be a claim-right, and

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[35] George, Kathryn Paxton. "Sustainability and the Moral Community." *Agriculture and Human Values* 9.4 (1992): 48-57, 50.

building on the expanded concept of heath care for which I already argued, it goes far beyond mere medical care.

In this chapter I am suggesting that it is neither individual charity, nor the flawed and often unjust institutions of states, who ought to be uniquely accountable for this kind of expanded health care. Instead, individuals can make claims on the ethical home in which they exist, and furthermore, this claim on the moral community is also a claim on individual members of the community, because in an ethical home each member is complicit in its formation, its practices, and its institutions.

While the ethical home is not in and of itself a standalone mechanism for the protection and fulfilment of rights, it can and should generate out of the values of the ethical home institutions (both formal and, if necessary, informal) that can fulfil rights. As previously noted, states often implicitly or explicitly exclude individuals and groups from accessing rights, in ways that may be necessary for the aims of the state, but do not necessarily align with broader aims of justice. Furthermore, holding states accountable for the fulfilment of rights is often a way to obscure or displace any individual responsibility – even the responsibility to hold other states accountable. By suggesting ethical homes are better suited to fulfill rights is not to suggest that this happen on an interpersonal or individual level.

Recalling my arguments in chapter two in support of the role of institutions for justice, I propose that ethical homes can foster what I am calling care justice. According to care justice, principles of attention, representation, and affiliation mobilize to involve home-makers in the process of attending to each other's needs, representing them in institutional practices, and affiliating with each other as a cohesive moral community (the ethical home). This means that each individual is implicated in the institutions and their practices which have duties to fulfill rights, and are further obligated to support the creation, promotion, or when necessary, reformation of such institutions.

My suggestion is that in the case of health care, this generates much stronger responsibilities on both individuals and public and private institutions to create the conditions for care justice and the provision of health care among fellow members. This does not mean each individual is responsible for paying for the care of, or directly nursing a fellow ethical home member, though they could. It means that we must take responsibility for both backward-looking, at the practices that lead to exclusions from the full spectrum of care including health care, and for the forward-looking practices and values that we want to endorse and enact within our ethical homes.

Christine Galarneau argues in her book *Communities of Health Care Justice* that smaller, subnational communities that engage in social relations can address justice in health care better than on a national scale. It should be clear by now that I am sympathetic with Galarneau's position and objectives. Although I take Galarneau as willing to acquiesce too greatly to pre-existing structures at the social and health care levels, and merely adding in features of community-engaged health care.

Yet what is useful about Galarneau's account is the observation that micro-communities already are more effective at health care provision. Moreover, given this effectiveness, a community-based approach should be extended and fostered in order to take shared responsibility for health care within communities, engage the community in needs assessment, and practice the inter-relational endeavor of health care.[36] Galarneau offers a vision for what kind of health care we can build on preexisting systems, and points to the ways that health care in communities is already demonstrably effective. Beyond this, however, she does not provide a way in to why and how we take responsibility in general, and particularly how we take responsibility for those we have previously excluded from communities, including micro-communities that support health care.

But connecting Galarneau's practical observations and analysis to my conceptual framework for complicity in ethical homes, we could imagine that micro-communities could enact health care justice, apart from larger mechanisms such as the state. Such communities may overlap with codified cities or counties, or even small states, though they need not subscribe to these arbitrary borders. They will likely occur around collections of people, in the way many communities arise in settings with a metropolitan hub, or around a key natural resource.

Given the inequitable distribution of resources that are concentrated in major urban centers (such as to hospitals and medical technology) or natural resources (like lakes with a secure fresh water supply), it may be necessary to redistribute access to ethical homes, and consider how people can move their literal home in order to participate in an ethical home with greater resources. Or it may be necessary to recognize different layers of ethical homes, such that some larger layers ensure the provision of certain resources that are not possible inside smaller communities. The nuts and bolts of this kind of access and distribution is beyond the scope of this project, but will be important to work out in order to put the theoretical framework into practice moving forward.

As an example, if I imagine myself living in an ethical home with one of the undocumented patients in my earlier chapters, I might note that she and I are sharing in the practice of community-making together. We both labor in the same community and pay into shared social goods such as roads and schools. Perhaps we have children that attend public schools together. Or perhaps we

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[36] Galarneau, Charlene. *Communities of Health Care Justice.* New Brunswick: Rutgers University Press, 2016.

both use the same public library or community gym or mass transit system, participating in these systems through our time, presence, financial support, and commitment. I need to recognize that her choice to migrate to the US is not only an isolated individual choice, but one bound up in contingent circumstances: the completely arbitrary fact that she was born elsewhere, and I was born in the US, among other things.

Furthermore, I need to recognize that I exist as a beneficiary of a system that grants me citizenship, and this citizenship affords me access to public health care, or to the right to work a job that extends private employer-based health care coverage, or both. She cannot access either of these goods. I am complicit in a system that both values health care, and that disvalues access to care on the part of those who migrate illegally, despite the fact that she and I are both participating in our local community, likely with some degree of interdependence on each other.

Given these facts, I take it that I, and others who live in community with her, have obligations to her, possibly directly expressed toward her, but more likely expressed as obligations to reform a system that excludes her from just care, despite being a member in our shared ethical home. Doing so recognizes backward-looking complicity in the harms of exclusion from social recognition and health care access, and forward-looking complicity in bringing about necessary change and revised practices.

Objections and Replies

I will address four types of concerns about the program I just laid out. Then I will conclude by returning to the heart transplant example as a case of complicit care in a health care context to illustrate the move from theory into practice within complicit ethical homes. One criticism is that the scope of ethical homes I have provided could justify a call for universal care, in which all persons would need to be included in an ethical home. Second, is the worry that this model obligates us to show some kind of love or affection for those for whom we care. Third, is the worry that my account does not yield any kind of institutional warrant that is required of acting in the name of justice. And fourth, there is a concern that in rejecting certain accounts of property rights by favoring a concept of home instead of house, my account cannot make sense of the goods necessary for care, and especially necessary for health care.

The first objection I will call the worry about care everywhere. If moral communities are plastic in the ways that I am suggesting, and may require us to expand and enlarge who is recognized as a member in an ethical home, then do they risk obligating us to a universal program of care, including universal health care? I hope it is clear that although I think a virtue of the structure of ethical homes for which I am arguing is that they can be expanded or remade to reflect more appropriately inclusive membership, this is not the same as infinitely extending out the boundaries of our ethical homes.

A separate virtue of ethical homes is that they can also be specific. I agree with Galarneau that communities are an overlooked but effective site of health care provision, and care provision more generally. Furthermore, I am suggesting that it is possible to have multi-layered ethical homes, and some might be quite expansive. Perhaps, for example, we recognize people, animals, and plants across the globe as members in our ethical home with rights and responsibilities for environmental care and reducing the impact of climate change. But this concept of an ethical home is compatible with also recognizing our immediate local community, say, within a radius of only several miles, as possibly the appropriate scope of our ethical home with regards to health care (or education, or transportation infrastructure, or any other good this particular ethical home values).

My point is to identify a moral community that is narrower, and therefore in my view, more actionable and accountable, than something as broad as humanity. Or even as something as broad as the state, which, as I have already argued, is rife with other problematic exclusions and limitations. What I am suggesting is that we might have duties to care for particular people internal to our communities who, through other mechanisms of membership or other iterations of groups, are left out. And it is to these particular individuals, due to our historical and continued complicity in creating or maintaining the circumstances according to which they are particularly vulnerable, we have obligations.

Furthermore, even within our ethical homes, the mechanism of individual complicity in the care of our fellow home members may not come into play. In practice when people have effective insurance, caretaker networks, adequate finances, and access to care, they may not call upon or invoke rights claims on others within the ethical home. It may not be necessary to overhaul an entire system (at least not at first) of health care provision to nonetheless extend necessary, and entitled, care to those who are currently without it. A first step might entail advocating for programs for the uninsured, or for the removal of citizenship or immigration status as part of applications for health insurance. We do need to figure out how to address the needs, and what I am arguing are the rights, of those with whom we share in community, for which we need to take individual responsibility in our contribution to the exclusions from care that occur in our ethical homes.

A second worry is about love and affection. One connotation of "caring for" someone implies love and affection for them. By caring for others, including strangers or those whom we have not historically recognized as identifying into or with, are we obligated to show love or affection for them? I hope to have made clear that my account of care is not on an affective level. I am not modeling my vision of care on the kind of care that occurs in parent-child relationships, as care ethics frequently does. There is importantly a need for care to be shown to and directed at particular persons, due to proximity and other features of embedded engagement (i.e. in a broad concept of home). But this is distinct from needing to show love, or even affection or friendship, for people. Care need not be love or affection or intimacy. It can and should be, at its core, about attention, representation, and affiliation.

I previously argued for this kind of practice to be described as care justice, which is also a form of recognition respect, that is separate from affective feeling. What my account does want to avoid is the absence of caring mechanisms that we tend to permit as justified for those who have failed to generate affective, loving, or friendship relationships in their lives. On my view, while no one is due these social experiences as a claim-right, their absence is not a justification for the absence of care, and it may in fact produce greater obligations for care justice. I further want to acknowledge that this view runs counter to many of our intuitions and assumptions about people, their worth, and the chosen nature of their relationships and behaviors. But although it runs counter to our initial intuitions, I think it is the correct view of rights to, and obligations for, certain kinds of care.

The third worry regards institutional warrant. An objection might run that my program of ethical homes, and the creation of moral community in ethical homes through the framework of complicity, does not do any better job than other programs, such as care ethics, at setting forth institutional warrant. This may be true, in part. My approach does not, at least at this juncture, reshape a political agenda such that it accounts for better inclusions within a state, or state obligations, for example. Yet I maintain that it can address and overcome failures that occur at these broader institutional levels, and intervene in instances in which we tend to otherwise defer our action to the state, and fail to accept individual or local accountability.

My hope is that an ethical home can yield individual responsibility within a collective, because there is collective responsibility in the first place, and this may be a collective responsibility to reform existing institutions, or establish new ones, that can address these demands of care justice. The institutional warrant comes about through the obligation on individuals to amend unjust or insufficient practices, and to generate new ones, including institutional practices such as within health care settings including within hospitals, clinics, and in health care payment schemes.

Fourth, is a concern about material goods and the status of property. There might be a worry that my critique of property rights and property-based models of rights in previous chapters, in favor of ethical home-based rights, overlooks the many material goods that are relevant to health care. I am not ignoring that goods are at stake here: they are. They are goods of resources, care, effort, money, technology, some of which are more limited than others, but they are all in some relevant ways limited. As previously noted, although I am arguing against certain models indexed to property rights, which I take to be exclusionary, and, at least historically if not presently, unjust, this is not to say we cannot own and control things.

But I do think that given the injustice of ownership schemes, we might have good reasons that we are required to share what we own, much more than we might currently realize, with those with whom we share in our ethical homes. This is more than a mere duty of charity, beneficence, or kindness. On my view, it is an obligation, entailed by the rights of others and ourselves, warranted by the moral community in which we participate, to respond to claim-rights of those within our ethical homes, including a claim-right to an expanded notion of health care, of which we are also the authors, protectors, and enforcers.

Coda

To return to the case of heart transplant recipient criteria: the existing guidance reveals a culmination of the kinds of thinking against which I have argued throughout these chapters. The criteria adhere to a strongly biomedical concept of health, and reflect a protection of a normative concept of health, rather than an expanded concept of health care. They rely on a logic of choice, reflected in the ways in which substance use (tobacco, alcohol, and illicit drugs), body weight, and social networks of care, are all justified as relevant categories for refusing to list a person for a transplant. To justify these exclusions, we should presume they are factors assumed to be within the control of the patient, and a reflection of her choices rather than her circumstances, including her oppressive or unjust circumstances. Finally, they misconstrue care, relying too greatly on a privatize, interpersonal concept of care as that between family or friends, and cultivated within intimate relationships.

In the previous chapter I acknowledged that these criteria respond to priorities reflected in transplant medicine to optimally use scarce resources. There are limited hearts, and programs want to bring about successful transplants. This justifies selecting one potential recipient over another because she is predicted to best use the resources of a donor heart. She is predicted to fare better, have a more successful transplant surgery, and live longer thanks to a new heart.

In a way it is curious, though, to say that one patient over another is predicted to best use the resource. Between two heart failure patients, if only one will receive a heart this means that one will have a chance at a prolonged life through transplant, and the other will likely die much sooner. Both presumably view their lives as worth living, and likely think that any shot at a longer life is a good use of the resource. The aim of medicine is not to decide whose life is worth more, or worth extending. The heart transplant recipient guidelines note that the psychosocial criteria for transplantation candidacy risk making judgments about whose life is worth prolonging, and advises against this misuse of the criteria.

Yet the criteria assume an idealized, universalized concept of justice that fails to attend to the ways in which the scale of justice will already be tipped in the favor of some over others. Effectively, the criteria occlude the many ways in which embedded assumptions about health, about choices, and about justice itself, all lie not too deeply below the surface.

We know that social determinants of health (economic status, geographical setting, race and ethnicity, sex as well as gender identity, as well as genetic and epigenetic factors) contribute to whether or not someone has heart disease or heart failure. Moreover, they contribute to whether someone has become addicted to tobacco, alcohol, or illicit drugs;[37] whether she has access to support systems and treatment for those addictions; to obesity[38] and whether or not someone has access to nutritious foods or lives in a food desert or otherwise cannot afford to prepare and eat a nutritious diet; and whether she has the ability and time for exercise around other life and work demands.

Criteria that initially look neutral, mere facts about someone's existence, body, and health, or that appeared to reflect autonomous choices a patient has made about her lifestyle, body, and health,

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[37] Baumann, Michèle, et. al. "Associations of Social and Material Deprivation with Tobacco, Alcohol, and Psychotropic Drug Use, and Gender: A Population-Based Study." *International Journal of Health Geographics* 6.1 (2007): 50-62; Haustein, Knut-Olaf. "Smoking and Poverty." *European Journal of Cardiovascular Prevention & Rehabilitation* 13.3 (2006): 312-318; Mulia, Nina, Laura Schmidt, Jason Bond, Laurie Jacobs, and Rachael Korcha. "Stress, Social Support and Problem Drinking Among Women in Poverty." *Addiction* 103.8 (2008): 1283-1293; Rose, Richard J., Ulla Broms, Tellervo Korhonen, Danielle M. Dick, and Jaakko Kaprio. "Genetics of Smoking Behavior," in *Handbook of Behavior Genetics*, 411-432. New York: Springer, 2009.

[38] Zhang, Qi, and Youfa Wang. "Socioeconomic Inequality of Obesity in the United States: Do Gender, Age, and Ethnicity Matter?" *Social Science & Medicine* 58.6 (2004): 1171-1180.

start to look less and less in an individual's unique control. This is not to remove all responsibility from individuals for their actions, but it is to recognize that some actions may be more complex than they first appear, and are the products of both chosen and unchosen circumstances in which they find themselves. This is even more true of other psychosocial requirements for transplant: having access to caregivers, having adequate financial resources, and caregivers having access to adequate financial resources to be able to devote their time and attention to the patient's care.

Again, I do not want to pretend that these physical and psychosocial features do not matter to heart transplant success: they do. But just because these criteria produce the best use of a donor heart in the eyes of a justice-oriented calculation within medical practice does not mean that they are in fact just, all things considered. Young notes that there is a myth of ideal community in which social relations are unmediated and differences between individuals and between groups are denied.[39] Heart transplant guidelines subscribe to the myth of an ideal community that flattens difference. But as Young and other feminist scholars point out, this attempt at universalization does an injustice. As Young says, "justice in a group-differentiated society demands social equality of groups, and mutual recognition and affirmation of group differences."[40] I think we can extend this thought not only to difference between groups, but differences among individuals because of their intersectional identities.[41]

We might also interrogate what other values the transplant recipient criteria uphold: one is, as already stated, a biomedical model of health. This already does an injustice. It implicitly values those who meet a normative ideal of health, which is revealed in the ways the criteria prioritize those without cognitive deficiencies, and excludes those with particular co-morbidities.[42]

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[39] Young, *Justice and the Politics of Difference,* 232-233.

[40] Ibid., 191.

[41] Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color."

[42] The criteria note that it may cause greater harm to someone with cognitive deficiencies to undergo a major surgery and the required post-operative care and the various risks affiliated with the surgery and recovery given their inability to adhere to treatment ("The 2016 International Society for Heart Lung Transplantation Listing Criteria for Heart Transplantation," 4 and 8). While this analysis of weighing potential risks and harms with benefits is necessary in evaluating every potential transplant candidate, we might worry about what assumptions are being made by providers about the capacity of a person with an intellectual disability and if this is always a fair analysis, free of bias. Additionally, with regards to co-morbidities, it seems fair to recognize that certain co-morbidities may increase complications and decrease likelihood of a good recovery, but again we might simply wonder if these are always evidence-based conclusions or if they reflect assumptions about the value of certain people's lives, such as those with HIV. The 2016 revised international guidelines recommend that HIV positive candidates can be considered for transplant if their disease meets

A second implicit value they perform is to support success or mastery in medicine. It is possible that while a certain vision of justice is given as the reason for the criteria, and the desire to best allocate a scarce resource, the way "best" is defined is through a particular understanding of a successful transplantation according to which a patient recovers as well as possible and lives as long as possible. I would think both patients and providers would find this to be a positive outcome. But is this the only vision of justice relevant for transplantation?

We might also wonder if this is the only way to understand the "best" outcome? For someone whose life has a chance of being prolonged any among, she might find that prolongation of life to be the "best" outcome in her individual circumstances. Could justice not also attend to adjusting for the set-backs some individuals have faced and pay particular attention to their needs in the name of justice?

We see other embedded values internal to the norms of medicine reflected in the criteria: a key principle in medical practice is that of autonomy, which is the autonomy to make a specific medical decision or set of medical decisions. Patients are deemed able to make autonomous medical decisions when they have capacity to make such decisions. Capacity is assessed according to four criteria: patients show understanding of the various options open to them, they appreciate the risks and benefits of the various options, they demonstrate a reasoning process that leads them to take the decision they do, and they can communicate a choice. Importantly, patients are only assessed for capacity to make the decision(s) at hand. So, what happens when we import notions of autonomous decision-making into other realms of patients' lives, when these realms become criteria for their medical care?

We end up treating other choices, like the choice to use drugs, or the choices resulting in the alienation of family who could be potential caregivers, as choices that patients could have arrived at with understanding, appreciation, and reasoning, in which their actions are a communication of a clear choice. As already discussed, there are limits to a logic of choice, and autonomy is less individual and far more socio-historically influenced, than the neat picture of capacity and autonomy engaged in discreet medical decisions.

Choices may more often than not be influenced by other overt or covert background conditions, that may or may not be in an individual's control. Addiction may be pathological.[43]

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certain criteria, although individual transplant programs can and do treat HIV as an absolute contraindication, as evidenced by the publicly posted Johns Hopkins criteria as of April, 2019.

[43] Leshner, Alan I. "Addiction is a Brain Disease, and It Matters." *Science* 278, no. 5335 (1997): 45-47.

Someone might not have saved money because they were excluded from careers or employment positions with higher earning potentials for a host of reasons.[44] We tend to imagine a white, educated, middle or upper middle class, probably male, patient. We don't imagine the woman who earned 76 cents to the male dollar, or the abused spouse whose abuser garnished all her wages,[45] or the person with a deep history of trauma and mental illness who was not supported to develop the kinds of deep relationships that would lead someone to offer to be his caretaker in a time of need.

When we approach these cases with more nuance, we can recognize that these are not just personal failures, but community failures. The community is responsible for its norms, for its values, and its practices. My claim in these last chapters is that individuals are responsible as complicit members of the community for establishing such norms, and need to take responsibility for dismantling them when necessary. As Young said, to achieve justice in a society in which groups are differentiated means we would need to create the conditions for social equality between groups, and mutual recognition of and despite difference.

In cases of potential heart transplant patients, this might look like recognizing, and restructuring, group differences that have led some to better meet the psychosocial (though also to an extent physical) criteria for transplant. It requires either revising the criteria to generate greater social equality between groups that have historically been unequally due to lack of recognition or disvaluing of difference. Or perhaps more fruitfully, it requires maintaining the criteria in place, and better supporting conditions to help individuals meet the criteria.

We are talking about scarce resources, and the language surrounding donor organs describes them as being the "gift" of life. The language of gift is helpful to recall that no one is necessarily entitled to a donor heart. This is a fairly miraculous technology that has been developed, and that hinges on another person's usually untimely death, to produce the opportunity for a new heart to be made available to someone who needs it. Yet just as we might say that no one is "owed" a donor heart, we can see clear instances in which someone ought not be denied a heart because of social and historical factors that result in their exclusion from criteria designed to foster successful transplantation.

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[44] Gottschalk, Peter. "Inequality, Income Growth, and Mobility: The Basic Facts." *Journal of Economic Perspectives* 11.2 (1997): 21-40.

[45] Gronau, Reuben. "Inequality of Family Income: Do Wives' Earnings Matter?" *Population and Development Review* (1982): 119-136.

Recall that my argument is that complicit ethical homes recognize the ways in which individuals shape and are shaped by the moral community that they find themselves in, and individuals are participants in forming, and when necessary reforming, their ethical homes. The ways in which we benefit from or reinforce the histories, institutions, and values of the moral community render us complicit members of it. This is a stronger obligation to the moral community than other routes into membership, and render ethical home-dwellers as responsible to the rights claims of others with whom they share their home.

In the ethical home, I must take responsibility, for example, for reproducing a community in which fellow community members to whom I am interconnected and entangled, are excluded from accessing medical care, health insurance, psychosocial supports, and proper nutrition. This makes me complicit in the community, and in the practices that the community rehearses. Thus, I am accountable for addressing their needs as particularly vulnerable community members, in part because I am accountable for perpetuating, if not creating, some of the circumstances that render them especially vulnerable.

Ethical homes have obligations to handle cases such as heart transplant, or other medical issues, according to a different set of obligations, and different conception of justice, than how medicine has approached such issue up to now. Ethical homes need to respond with care justice. The objective of care justice is not necessarily to respond equally well to all persons, but to recognize that some response is due to those with whom we engage in a moral community.

Care justice demands that we care for those within our moral community through the practices of attention, representation, and affiliation, in which we attend to the needs of our co-community members and recognize them as community members. We represent their interests and needs, and they have space to represent their own interest in needs. The processes of attention and representation yield affiliation between members of the moral community to cohere together as an ethical home.

In practice, I am not advocating for throwing out the heart transplant recipient criteria. These criteria might rightly reflect the best chance for successful transplant, and respond to the reality of donor organs being a limited resource for which we need an allocation mechanism. However, I am imaging how ethical homes can enact practices of care justice to bring more community members up to the level of meeting heart transplant recipient criteria.

This could look like creating policies for caretakers of transplant patients to be paid for their care work (as well as protecting their job security when returning to work, as currently occurs within only a limited scope per the Family Medical Leave Act in the US). Similar to how disability benefits are paid to those who cannot work temporarily or permanently due to disease or disabling condition, benefits could be paid to those who care for someone else temporarily, or even permanently.[46] If safety net systems were in place to compensate intimate care-givers, these same systems could also provide support to compensate non-intimate care-givers, so that if one were without family or friend social networks they would not necessarily be excluded from accessing caregivers.

We might further imagine and advocate for systems in which safe and secure housing were available for those who do not already live in conditions that would support their post-operative recovery. Or, we might advocate for and reform mechanisms for health insurance internal to an ethical home. Health insurance could be extended to those who are members of the ethical home, even if they are excluded from nation-state membership.

Housing and care-giver compensation might require complicit home-dwellers in the moral community to contribute to a health care fund, based on their level of ability, and to redistribute the unjust allocation of financial and material resources. This obligation would not be to merely contribute to a charity fund, through an imperfect duty of beneficence. If this were the case then I think the obligation could be compatible with a state-based system in which the state is primarily accountable for the protection and fulfillment of rights. On that system, individual citizens would be required to respect rights, but not to protect or fulfill them.

Such contributions would occur only when and if individuals wished to make them, donating their money through or time (such as through activism or direct care). They would remain acts of kindness, or charity, or beneficence. However kindness and charity cannot meet the demands of claim-rights. On my view it is an absolute obligation to do one's part to protect and fulfill the rights of others in the moral community – not just to respect them.

Perhaps a human rights framework could yield similar objectives, to redistribute access to care, to recognize rights to psychosocial goods, and to better extend access to material resources. I think a human rights approach is friendly to the thought that all humans have social, economic, and political rights. My concern, particularly as discussed throughout the third and fourth chapters, is that human rights frameworks encounter difficulty in attributing concrete duties to particular agents

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[46] Much has been written about the dichotomy between private and professional care, and my suggestion is that this distinction is a false one. Professional care rightly compensates someone for care work, but still relies on another person being able to afford to purchase care, which does not solve the problem of restricting care to those who affluent enough to afford it.

obligated to fulfill them. So, a general right to care does not implicate any particular institution as accountable for fulfilling the right to care. Moreover, because these are rights due to all humans, it looks like a set of widely-distributed rights, without equally widely distributed correlative duties.

But then we can say that although human rights are due in virtue of one's humanity, it is states who are by and large accountable as the obligated actors to fulfill (and protect and respect) these rights. This returns me to my observations about how states narrowly attend to their own citizens, excluding many who ought to be due "human" rights as humans, but in practice do not receive these rights because states understand their obligations to be limited to their citizens, and not extended to all humans.

My point is that obligation generated via complicit participation in the moral community is a stronger, and also more specific, kind of obligation. And when there are other goods to redistribute: goods of recognition, political recognition, social recognition, ethical home dwellers are complicit in the prior failures of recognition. The attribution of blame is also what generates their accountability to rectify harms. This starts by advocating for and enacting new policies and practices that extend proper recognition, and fulfill the rights of those with whom they share the ethical home. This is a duty, not a favor, on the part of individual participants who co-engage in ethical home-making.

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