Dignifying Decisions: The Role of Dignity in Surrogate Decision-Making

Jeffrey Pannekoek
jpanneko@vols.utk.edu

Follow this and additional works at: https://trace.tennessee.edu/utk_graddiss

Part of the Applied Ethics Commons

Recommended Citation
https://trace.tennessee.edu/utk_graddiss/7357

This Dissertation is brought to you for free and open access by the Graduate School at TRACE: Tennessee Research and Creative Exchange. It has been accepted for inclusion in Doctoral Dissertations by an authorized administrator of TRACE: Tennessee Research and Creative Exchange. For more information, please contact trace@utk.edu.
To the Graduate Council:

I am submitting herewith a dissertation written by Jeffrey Pannekoek entitled "Dignifying Decisions: The Role of Dignity in Surrogate Decision-Making." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Philosophy.

Kristina Gehrman, Major Professor

We have read this dissertation and recommend its acceptance:

Adam Cureton, Georgi Gardiner, Annette M. Mendola

Accepted for the Council:

Dixie L. Thompson

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)
Dignifying Decisions: The Role of Dignity in Surrogate Decision-Making

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Jeffrey Pannekoek
August 2022
Dedication

To Brittany—who is extraordinary in everything she does—and to Zowie and Rowan, who motivate and sustain me in all things.
Acknowledgments

Throughout the writing of this dissertation I have received a great deal of support and assistance. I would first like to thank my supervisor, Dr. Kristina Gehrman, whose expertise as a philosopher and writer has been invaluable in the realization of this project. Your feedback has brought this project to a greater level of clarity and relevance. Thank you for your guidance and mentorship!

I also want to thank my other committee members, for their time, feedback, and insights: Dr. Adam Cureton, who can make Kant comprehensible for anyone and whose philosophy of disability seminar brought me to the topic of clinical ethics; Dr. Georgi Gardiner, for pinpointing ambiguities and implications, and; Dr. Annette Mendola, who has provided me with access to clinical ethics at the UT Medical Center. This project and my professional aspirations in clinical ethics would never have been realized without her. Thank you all for your confidence and support!

I have received several funding and fellowship opportunities that have contributed to this project. In recognition of this, I want to thank the organizers and fellows at the Andrew W. Mellon Foundation/Humanities Without Walls Pre-Doctoral Career Diversity Summer Workshops (2019), the College of Arts and Sciences (Thomas Fellowship, 2020-21), the Prados Fund (Prados Summer Dissertation Fellowship, 2021), the College of Humanities and Social Sciences (Graduate Student Fellowship, 2020), and the University of Tennessee Philosophy Department and Graduate School.

Pieces of this project have been presented at the Intermountain West Philosophy Conference (2018), UC Riverside Graduate Student Philosophy Conference on Agency (2019), and the Tennessee Value and Agency Conference (2019). I have also received welcome feedback during my job talk at the Cleveland Clinic. I would like to thank everyone who contributed to these opportunities. I would also like to acknowledge Dr. Glenn Graber, Dr. John Hardwig, and all of the members of the UTMC Ethics Committee for their conversations and insights.

Thank you to the instructors at Utah Valley University for their unique commitment to their undergraduate students, in particular Dr. Pierre Lamarche, Dr. Chris Weigel, Dr. Michael Minch, Dr. Karen Mizell, Dr. Shannon Mussett, and Dr. Karin Anderson.

On a personal note, I want to thank my parents for their decades of support. And Tylor Cunningham and Adam Wilson, who are the Form of friendship. And finally, I want to thank Brittany Hentzell-Pannekoek, for her confidence and encouragement, her endurance during my years of graduate school, and for her editing skills.
Abstract

Dignity refers, broadly speaking, to a kind of status that is intrinsically connected to certain norms. Often, we think of dignity as the status of having inherent value, which entails that certain kinds of treatment are morally impermissible. References to dignity are pervasive in clinical ethics, where the concept is called on to do a broad variety of work, including bolstering claims about patient-focused health care, advocating in favor of and against euthanasia, and supporting an infinite number of particular medical decisions. In stark contrast to its pervasiveness, the conceptualization of dignity is still an unsettled issue, in particular in the clinical ethics literature.

In this project, I first discuss the Kantian roots of our contemporaneous universal conception of dignity. I demonstrate the problems that the universal account of dignity has inherited from this view, including the potential exclusion of those with compromised capacities and the ability to substantiate conflicting analysis and recommendations for action. In the context of clinical ethics, it is vital that these moral conflicts are navigated and resolved. This means that we stand in need of a new account of dignity.

It is my objective to argue for a relational conception of dignity that is grounded in a person’s narrative. On this view, dignity is not a static status of inherent worth, but a success condition of interpersonal relationships. Dignity is achieved when people respond appropriately, that is in dignifying ways, to a person’s narrative. Here, narrative is made up of a set of elements that constitute the structure of a person’s life. This includes their testimony, actions, preferences, values, relationships, and institutional ties. The relational understanding of dignity is able to support standards of conduct and guide decision-making in concrete cases of moral conflict. I subsequently demonstrate the virtues of this account by applying it to the challenging issue of surrogate medical decision-making for Alzheimer’s patients. Finally, I argue that one of the implications of the narrative account of dignity is that we must reconsider the traditional ethics case format, since this leaves out many of the narrative elements that are vital in surrogate decision-making.
Table of Contents

Introduction.................................................................................................................................1
  Why Dignity?..............................................................................................................................1
Relational Dignity..........................................................................................................................5
Surrogate Decision-Making...........................................................................................................8
Cases...........................................................................................................................................11
Outline.........................................................................................................................................15

CHAPTER 1: (Universal) Dignity in Philosophy........................................................................17
  The Dignity Landscape...............................................................................................................17
    Ten Kinds of Dignity..................................................................................................................17
    Surveying the Dignity Landscape............................................................................................22
    Mapping the Dignity Landscape...............................................................................................24
  Dignity in Kant............................................................................................................................28
    Kant and the Universality of Morality......................................................................................28
    The Moral Law and Dignity......................................................................................................31
  Universal Dignity.........................................................................................................................33
    From Kant to Universal Dignity..............................................................................................33
  The Problems with Universal Dignity.......................................................................................39
    The Problem of Irresolvable Conflicts....................................................................................39
    The Problem of Paternalism.....................................................................................................40
    Universal Dignity and the Problem of Medical Assistance in Dying.................................42
    Reason, Dignity, and Disability..............................................................................................46
    Moving Forward.......................................................................................................................48

CHAPTER 2: Relational Dignity Three Ways..............................................................................50
  David Luban’s Relational Human Dignity and the Law.............................................................50
  Suzy Killmister’s Dignity and Personal and Social Values.........................................................60
    Three Kinds of Dignity..............................................................................................................60
    Human Dignity..........................................................................................................................63
    Three Kinds of Damage to Dignity..........................................................................................66
    Dignity and Claims....................................................................................................................67
    Killmister’s Tapestry of Dignity and Case Studies..................................................................71
    Critical Discussion....................................................................................................................73
  Linda Barclay’s Relational Dignity in Health Care.................................................................75

Chapter 3: Narrative-Based Relational Dignity........................................................................78
  A New Kind of Relational Dignity..............................................................................................78
  The Nature of Narrative..............................................................................................................79
Narrative, Story, and Testimony................................................................. 79
Elements of Narrative.................................................................................. 81
Narrative and Literary Theory..................................................................... 84
Are There Necessary and Sufficient Conditions for Narrative?................ 91
Narrative-Based Relational Dignity............................................................. 92
Relational Dignity....................................................................................... 93
(Only) Standing in Relation to Oneself and Other Worries....................... 95
Meeting the Desiderata of Dignity............................................................. 97
Respect, Autonomy, Humiliation, and Paternalism in Relational Dignity... 98
Narrative-Based Relational Dignity through the Cases............................... 99
Dignity at the End of Life.......................................................................... 99
Dignity and the Role of Irrationality.......................................................... 102
Recently Acquired Disability, Deciding to Die, and Sour Grapes.............. 104
Extending Dignity...................................................................................... 110
Dignity After Death................................................................................. 110
Is Relational Dignity Human Dignity?...................................................... 112

CHAPTER 4: Relational Dignity in Surrogate Decision-Making.................. 115
Uncertainty and Surrogate Decision-Making............................................. 115
Relational Dignity and Surrogate Decision-Making.................................. 117
Relational Dignity and Alzheimer’s Disease.............................................. 122
The Nature and Consequences of Alzheimer’s Disease.......................... 122
Ronald Dworkin’s “Life Past Reason”....................................................... 125
Agnieszka Jaworska’s “Respecting the Margins of Agency”...................... 128
Alzheimer’s Disease and the Disjointed Narrative.................................... 134
Relational Dignity Analyses of Alzheimer’s Cases................................. 137

Chapter 5: Challenging the Traditional Case Format................................ 140
Relational Dignity through Narrative Cases............................................. 140
A Literary Case......................................................................................... 140
Rethinking (How) Do We Choose Our End?........................................... 145
Reconsidering the Case Format............................................................... 147

Conclusion............................................................................................... 150

References............................................................................................... 152

Vita............................................................................................................. 175
Introduction

A. Why Dignity?

In the winter of 2018 I had the opportunity to do a research project for the University of Tennessee Medical Center. They were revisiting their guidelines for decision-making and DNR-orders for unrepresented patients, and I wrote a brief on various models of surrogate decision-making. One underlying question in evaluating these models is: what constitutes a good decision? This question takes on added weight when we are deciding for someone else. This led me to think about how good practical reasoning can advance respect, dignity, and autonomy, and minimize paternalism and humiliation in surrogate decision-making. The closer I looked at practical reason, these moral terms, and their respective roles in decision-making, the more it seemed that these concepts are deeply intertwined. It’s difficult to offer an account of any of them without affecting how we conceive of the others. I decided to focus my analysis on dignity, because it is perhaps the most vexing of these interrelated terms. I also believed that dignity appears to play a foundational role in normative ethics more generally speaking, and may be conceptually prior to the other moral terms. So in considering my approach to the dissertation, the question came down to: what is dignity?

The question matters, because references to dignity are pervasive in clinical ethics, and the concept is called on to do a broad variety of work, including bolstering claims about patient-focused health care, advocating in favor of and against euthanasia, and supporting an infinite number of particular medical decisions. And when we consider related concepts such as autonomy, respect, humiliation, and paternalism, we can see that the term is ubiquitous. In stark contrast to its pervasiveness, the conceptualization of dignity is still an unsettled issue in the philosophical literature, as well as in the clinical ethics literature in particular. For instance, the Universal Declaration on Bioethics and Human Rights states that its aim is to “promote respect for human dignity and human rights” and sets out that this dignity constitutes the “fundamental equality of all human beings” (United Nations Educational Scientific and Cultural Organization 2005, n.p.).

In his article “Whose Dignity?” (2007), Harold Smith attempts to resolve the variability in usages of the term dignity in this declaration. He notes that the “UDBHR uses the term dignity nine times” and that it’s variably used to refer to human dignity, as well as in relation to persons, life, human beings, and individuals (Schmidt 2007, 578). This usage seems too irregular for the meaning to be constant, and as a result, it’s not clear what dignity means in this context. Susan Haack, in “Human Dignity: A Brief Overview,” echoes this idea, noting that the term dignity has become ubiquitous, and its “pervasiveness … has masked the extent to which its substance
has been lost” (Haack 2012, n.p.). Michael Rosen, in Dignity: Its History and Meaning (2018), remarks that the philosophical discourse on dignity is conceptually speaking very thin, and that “the lack of philosophical interest in the concept of dignity is striking” (Rosen 2018, 4). He points to the fact that the Routledge Encyclopedia of Philosophy lacks an entry for the concept (Rosen 2018, 4; still true as of February 2022). Similarly, the Stanford Encyclopedia of Philosophy produces no titular results for a search on the term. In The Nature of Dignity (2008), Ronald Bontekoe expresses a similar concern, noting that “we tend to appeal to our shared belief in the inherent dignity of human beings without inquiring too deeply into the original grounds that were offered for attributing dignity to human beings as such,” but as a result of this disconnect to the roots of dignity, “they have lost much of their power to convince” (Bontekoe 2008, 2). In these kinds of usages, dignity has the appearance of normative force. It can be used to express some moral significance that we intuit is there, especially when we find it difficult to give content to it. But dignity without an account of the essence of dignity, its evocation ultimately signifies nothing.

Pre-theoretically, we can understand dignity as a kind of status that is intrinsically connected to certain norms. For instance, we can think of dignity as a “moral achievement” where we have acted in a way that has realized certain norms (Bontekoe 2008, 1). Or we can think of this as the status of having inherent value as human beings, which means that certain kinds of treatment are morally impermissible. In Dignity: Its History and Meaning, Michael Rosen suggests that we have “a natural tendency to imagine dignity as an ‘inner, transcendental kernel’” (Rosen 2018, 9). In general, the universalist conception of dignity refers to ways of understanding dignity that say it is a basic, universal feature of all persons in virtue of which they deserve moral consideration and certain standards of treatment. The exact nature of the universalist conception of dignity is itself unsettled, but we encounter it as being instilled by God/G-d/Allah in the Abrahamic religions, or secularly as grounded in our humanity and guaranteed by political liberalism such as in the Universal Declaration of Human Rights, which recognizes “the inherent dignity and of the equal and inalienable rights of all members of the human family” (United Nations General Assembly 1948, n.p.). In western philosophical discourse, and in particular the broadly Kantian tradition, dignity is generally considered to be grounded in our capacity for reason (Kant 2006/c. 1785, 23).

Regardless of the source of dignity, the universalist conception of dignity entails that its subject has moral standing, which makes it an incredibly powerful force in normative ethics. It has the ability to infuse its object with moral meaning, and is able to impose hard limits on potential courses of action. This commendably entails the general moral impermissibility of reprehensible actions such as murder, torture, and bombing civilian populations. To have dignity means that the person has worth. They are valuable, either intrinsically or given their membership in a social system, and have moral standing independently of any other goals or ends. This
means that this person may never be fully instrumentalized, or treated merely as a tool toward some other purpose, because this would constitute a clear violation of their inherent value. To murder someone is to purposely and maliciously take their life. To torture someone is to use them entirely as a tool toward obtaining information or sadistic gratification. It is to reduce a person to an instrument, and to entirely discount their inherent worth. And to bomb a civilian population is to use an entire populace as fodder to forward a political agenda. Respecting the kind of value that dignity enshrines ensures that such actions cannot be morally justified.

It also enshrines the moral status of truth, upholding promises, and general beneficence as fundamentally good. Moreover, it supports the general freedom and autonomy of human beings. Dignity is intimately related to autonomy. Whereas dignity provides moral standing, autonomy is our capacity to exercise moral agency. To deny an agent their autonomy often entails instrumentalizing them in some way, and so violations of autonomy and violations of dignity tend to be coextensive. Take the issue of lying, and in particular the case of those seemingly morally innocuous benevolent lies. In “Autonomy and Benevolent Lies” (1984), Thomas E. Hill focuses on the kinds of lies that “are intended to benefit the person deceived, for no ulterior motives, and they actually succeed in giving comfort without causing pain” (Hill 1984, 253). The problem with benevolent lies is that they ultimately undermine the person’s autonomy, by depriving them of access to the full set of relevant facts (Hill 1984, 258, 266). On Martha Nussbaum’s account from her article “Objectification” (1995), this constitutes an objectionable form of titular phenomenon, which means that the person lying is not treating the person being lied to as a full agentive person with inherent moral worth (Nussbaum 1995, 257). As such, it constitutes not only a violation of autonomy, but one of dignity as well.

In spite of these strengths, the universal conception of dignity often fails to be an actionable standard, or an appropriate guide in more specific instances of moral decision-making and navigating moral conflict, at least when we try to apply it in straightforward ways. One of the reasons that a general notion of dignity is ubiquitous in political philosophy, normative ethics, and clinical ethics is that it functions as a cover for moral intuitions. Invoking dignity provides an argument with the appearance of force, but without a detailed account of the nature of dignity this is without real content. This can certainly be done in good faith and with the strength of conviction. But it can also be done merely to shield the person or institution wielding the term from moral critique. We can see this in the ways in which neoliberalism uses the language of human rights and dignity as cover for human rights violations and war crimes. For instance, in his 2002 State of the Union Address, George W. Bush stated that “No nation owns these aspirations [of liberty and justice], and no nation is exempt from them. We have no intention of imposing our culture. But America will always stand firm for the non-negotiable demands of human dignity: the rule of law; limits on the power of the state; respect for women;
private property; free speech; equal justice; and religious tolerance” (Bush 2002, n.p.). This was mere weeks after the invasion of Afghanistan, a little more than a year before the invasion of Iraq, and about two years before Joe Darby revealed the horrors at Abu Ghraib (Norris 2006, n.p.; Hersh 2004, n.p.; Greenewald 2019, n.p.).

For a medical example, consider the debate concerning active euthanasia. Canada has recently seen a rapid increase in the debate surrounding active euthanasia, as a bill was introduced seeking to expand end-of-life options (Parliament of Canada 2001). The organization Dying With Dignity Canada supports the availability of medical assistance in dying (MAID) as a means to “to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering (Dying With Dignity Canada, About, n.p.). By contrast, the Canadian secular organization Vivre dans la Dignité, or Living with Dignity, opposes MAID, and “promote[s] a vision of the human being based on the inherent and inalienable dignity of every person, regardless of their state of health.” (Vivre dans la Dignité, Our Mission, n.d., n.p.) This is based on their belief that “a human being possesses an inherent and inviolable dignity nothing can destroy” (Vivre dans la Dignité, Manifesto, n.d., n.p.). Both parties ground their positions regarding MAID in a conception of dignity that extends to all humans and that promotes a particular kind of conduct. Yet, they arrive at opposite conclusions as to what dignity entails with respect to MAID.

Part of the project of political liberalism is to ensure the freedom and autonomy of its subjects, and to secure the moral grounds for human rights. At a global scale, these guarantees must be universal, which means they need to be free from the constraint of particular cultural or religious outlooks, or moral theories. It is in this context that dignity is often used as a means of conveying secular and universal moral standing. Ironically, it is in pursuing this universal ideal that dignity loses its powerful potential. In becoming more universal, this liberal use of dignity has to divorce itself from its theoretical roots, which provided its explanatory and normative force. Now we are left with a general appeal to dignity that provides little substance to its moral claims, has only shallow explanatory power within the scheme of rights it promotes, and is unable to serve as a tool in navigating moral conflict. Regardless of their aims, universalist accounts of dignity can lead us astray, which is likely to leave already vulnerable people by the wayside. Furthermore, the universal conception of dignity is able to substantiate conflicting analyses of cases and can produce radically different recommendations for action. These moral conflicts must be navigated and, certainly in the context of clinical bioethics, resolved. This means that the concept of dignity needs work, and that the ethical implications of providing a coherent and practicable conception of dignity will be profound. In light of this, it is worth exploring a new account of dignity.
B. Relational Dignity

The previous section sets out both the importance of dignity and the problems its centrality in (applied) ethics entails. In response to these problems, I suggest an alternative account of dignity that is able to meet these challenges. In developing this account, I draw most significantly from two theorists, namely David Luban and Suzy Killmister. I share in common with them a conceptualization of dignity that departs from the Kantian foundation and focuses on personal and social norms and narrative elements. I also depart from each account in important ways, perhaps most significantly in my understanding of narrative as a broad set of features that are constitutive of the structure of the person's life. It is my objective to argue for a relational conception of dignity that is grounded in a person's narrative. This project supports a recent shift in the dialogue concerning dignity, away from the universalist conception and toward a relational understanding (Killmister 2010-2020b; Luban 2005-2009; Barclay 2016-2020).

In my analysis of relational dignity, I rely in the first place on David Luban’s account, as sketched in his “Lawyers as Upholders of Human Dignity (When They Aren't Busy Assaulting It)” (2005). This article offers an appealing account of dignity, which divorces it from its universalist terminological kin. As is clear from the title of his paper, Luban develops his understanding of dignity primarily in the context of the law. However, his relational view of dignity is more broadly applicable, and there are interesting parallels between law and medicine that illustrate its relevance. In particular, both medical and legal professionals run the risk of approaching their wards with undue paternalism. Luban explicates his understanding of relational dignity in terms of a person’s story and their ability to control how they represent themselves. This concerns a person’s social environment and how they are treated within that environment. Here, a person is dignified when they are treated in a way that coheres with their story. Why might we prefer Luban’s account of dignity? For one, it’s less metaphysically demanding than the universalist conception, which can be metaphysically mysterious. Moreover, the universalist account can (and frequently does) raise difficult questions about the limits of dignity, for instance in people with disabilities. Luban’s account respects the social nature of our (moral) lives and the centrality of storytelling to our conception of self. And as such, his account fits with our folk understanding of dignity, and can do a lot of the heavily ethical lifting we expected from an account of dignity. In short, Luban’s account of relational dignity is intuitive, metaphysically light, and does profound moral work—I’ll make the case for this interpretation early on in chapter 2. Nevertheless, Luban is vague in places where it matters. For instance, Luban suggests that dignity is grounded in the “ontological heft” of the individual’s “point of view,” where this appears to be equivalent to subjectivity (Luban 2005, 821-2). Moreover, this point of view is what facilitates the
person having “a story of one’s own” (Luban 2005, 821). Luban treats a number of these terms as roughly equivalent without giving any real independent account of what they mean or what their differences might be. This means that his account cannot simply be imported into other domains. It must be built out and revised in several places so that it can help in serving the application that I’m after in this project.

I also rely heavily on Suzy Killmister’s account of dignity, originally sketched in “Dignity: Personal, Social, Human” (2017), and subsequently thoroughly developed in her book *Contours of Dignity* (2020a). Killmister aims to offer a theory of dignity that accounts for the term in all of its varied usages. While she does not take her view to be exhaustive, it is able to support discussion of dignity with respect to personal and social values, the kind of dignity attached to certain roles and professions, as well as human dignity. She specifies three different threads of dignity, namely personal dignity, social dignity, and status dignity (Killmister 2020a, 21). Each of these are reflective of different kinds of norms, in particular personal norms that correspond to our self-respect, the norms of various communities of which we are a part, and the kind of norms that are affiliated with membership in a particular category (Killmister 2020a, 48-9, 23) Killmister also specifies three different kinds of damage that dignity can suffer, namely frustrations, violations, and destruction (Killmister 2020a, 39). Each of these specifies a different way in which the norms associated with dignity can be undermined. Why might we prefer Killmister’s account of dignity? The account is highly successful in reflecting many of the different usages of dignity, and making concrete the demands of dignity. And like Luban’s account, it is metaphysically less demanding than universalist accounts of dignity. While it’s significantly more complex than Luban’s account, it is theoretically more thorough and complete—I’ll make the case for this interpretation early on in chapter 2. The account of dignity as I propose it here is less exhaustive than that of Killmister. Given the practical constraints of the project, I focus on dignity as it is relevant to the individual in the context of healthcare, and I leave aside several other categories of dignity, including that of human dignity. It may be that, ultimately, the differences between Killmister’s account and my own come down to emphasis (on the individual vs human kind), scope (narrative vs. norms), and context of development (clinical ethics vs. normative ethics more broadly). In other words, Killmister’s account and my own may be compatible. I nevertheless argue that narrative offers a more appropriate grounds for dignity in the context of applied ethics, and clinical ethics in particular, than the one Killmister offers. It provides greater focus on the morally normativity aspects that are relevant in relation to medicine, and appropriately centers the individual as the locus of normative force.

On the view I propose, relational dignity is defined as a standard for deciding and acting that is based on a person’s narrative. There are a few things to notice here in the preliminary. First, it is clear from the definition that relational dignity
constitutes a normative standard. Given that this standard concerns right and wrong conduct, this standard is one of moral normativity. Second, this understanding of dignity is social in at least two ways: (1) much like any other theory of moral normativity it concerns interpersonal conduct, and (2) since the standard is grounded in the person’s narrative, the requirement is that one responds appropriately to this narrative. This kind of narrative engagement entails a range of social requirements and expectations, such as listening, uptake, reciprocity, and charitability. Finally, since the standard is grounded in the person’s narrative, this also means that the standard is, in an important sense, relative. This is very different from universalist accounts of dignity, which are generally egalitarian. This makes sense, since they concern the grounds of moral value, which is often thought to be equal across persons. This egalitarianism tends to extend to the kinds of treatment universalist views recommend, whether this be in terms of universal human rights, universal rules of action, or universal prohibitions of conduct. Relational dignity is not egalitarian or absolute in this manner. The right decision or course of conduct depends entirely on the person’s narrative and on the appropriate ways of responding to it, and as a result the view may coherently produce entirely different recommendations in apparently similar cases. This means that while dignity as a moral standard is itself objective, its application is particularist. The relational understanding of dignity, as I propose it, is able to respond to the problems raised in the previous section, because it can support standards of conduct and guide decision-making in concrete cases of moral conflict. It will also serve to reconceptualize and clarify a number of related moral terms, including respect, autonomy, humiliation, and paternalism, so as to form a coherent set of dignity-related terminology.

The project I’m laying out here can be thought of in two different ways, as either revisionist or clarifying. Given the broad variety of ways and contexts in which dignity is evoked, both of these are probably true: in some ways I’m advocating for revising our understanding of dignity, and in other ways I’m tapping into a usage that is already extant but undertheorized. Regardless, what I’m hoping to accomplish is to provide a framework for thinking about dignity in a way that is productive in shaping clinical decision-making. In terms of the scope of this project, I focus rather narrowly on clinical ethics. However, I aim for this account of dignity to be relevant to applied ethics more broadly. And while I don’t claim that the conceptualization of dignity I offer here is the view of dignity that will apply to everything, there are prima facie reasons for thinking that it can be such an account. The goal of the account is to apply to some of the most challenging situations and cases where other accounts of dignity have a more difficult time substantiating moral claims. If it can do this successfully, then this is evidence that this view is at least part of the correct view of dignity. I develop this understanding of dignity, first, in contrast to the universalist conception of the term (chapter 1); second, in
comparison to alternative relational usages of the term, using the work of several key theorists who have offered related accounts (chapter 2), and; third, in application to a variety of medical case studies and narratives (chapters 4 and 5). On my view, which is explicated and supported in chapters 3, dignity does not refer to the static status of inherent worth, but constitutes a success condition of interpersonal relationships: dignity is achieved when people respond appropriately—that is in dignifying ways—to a person's narrative. Here, narrative is constituted by a set of elements that make up the structure of a person's life.

C. Surrogate Decision-Making

The relational understanding of dignity gains particular relevance in the context of surrogate decision-making, which is an area in bioethics that demands attention. It involves some of the most vulnerable populations in healthcare, not merely because they are incapacitated for decision-making, but also because already vulnerable populations, including the homeless and elderly, are disproportionately represented in this group (Pope 2017, 945-6). Incapacitated patients, and in particular those who are unrepresented, are at high risk for undertreatment, overtreatment, and paternalism in the care decisions that are made for them (Pope 2017, 953). Models for surrogate decision-making generally focus on who should function as the surrogate or representative for the patient, but fail to address in a substantive way the standards for good surrogate decision-making (Pope and Sellers 2012ab; Pope 2015). This can, at least in part, be explained by how universalist accounts of dignity require the presence of an autonomous moral agent. If someone is unable to fulfill this role for themselves, then we are to find a substitute who can fulfill the autonomy requirement. Even if we set the patient's interests as the standard for decision-making, we nevertheless require an autonomous decision-maker to become the decider who has to answer the difficult questions. In this context, the narrative-based account of relational dignity has a significant payoff, as it is able to best serve the interests of some of the most vulnerable populations in healthcare.

Existing frameworks of clinical ethics often fail to provide adequate guidance in navigating these kinds of conflicts. For instance, the Principles of Biomedical Ethics helps practitioners and ethicists think about the competing values of autonomy, beneficence, nonmaleficence, and justice (Beauchamp and Childress 2006/1979). However, it does not provide the necessary tools for navigating a conflict between these values. Beauchamp and Childress admit this, noting “we acknowledge that moral frameworks of principles do not themselves resolve conflicts among principles and derivative rules” (Beauchamp and Childress 2006, 373). This is a recurring problem, as there is no established consensus on what such a framework ought to look like. Moreover, it is often thought that either an adequate or an ideal
framework will be able to fully resolve moral conflicts. This, though, is unrealistic, given the role of uncertainty in medical decision-making, and the ways this uncertainty is exemplified in cases of surrogate decision-making, and in particular in those of surrogate decision-making for unrepresented patients.

Medical decision-making often entails navigating a vast web of uncertainty, some of which is inherent in medical decision-making and some of which is circumstantial. Good medical decision-making must recognize the different kinds of uncertainty that exist, so that contingent uncertainty can be minimized, and inherent uncertainty can be properly acknowledged and navigated. In ordinary cases, uncertainty is resolved—not absolutely, but pragmatically—by the patient’s exercise of their agency. In deciding in a sufficiently informed and capacitated manner, the patient takes responsibility for the course of action. In the case of an incapacitated patient, the very act that ordinarily sanctions the decision, namely the autonomously deciding in light of sufficient information including that concerning uncertainty, is missing. The agent does not get to resolve the uncertainty themselves. As a result, further substantiated in chapter 4, there is no perfect, morally unproblematic medical decision-making in the case of an incapacitated patient. The result is always morally fraught—tinged by solipsistic uncertainty. The best we can do is to develop frameworks for better surrogate decision-making. This does not mean that surrogate decision-making is a bad thing, or something to be avoided. As ensuing chapters demonstrate, when the situation calls for it, surrogate decision-making is the best way to move forward. It offers the best means of ensuring dignifying treatment. At the same time, though, it is important to avoid complacency, and remember that good surrogate decision-making is always a multifaceted and compromised process. We must recognize it as an important and necessary tool, that must be utilized with responsibility and with care, while also recognizing the losses that it entails. To be too easily contented with this process, is to put us on the path toward failing to respect the dignity of the person.

The global Covid-19 pandemic has unfortunately brought this issue into sharp relief. With millions of hospitalizations and hundreds of thousands of ICU admissions globally over the last two years, there has been a sharp increase in the number of cases of incapacitated patients who require surrogate decision-making. The current global pandemic has brought end-of-life questions to the forefront for many, and there has been a significant increase in advanced care planning (ACP) (Portz et al., 2020). In fact, some early data suggested a five-fold increase in ACP by April 2020 (Auriemma 2020, n.p.). Yet, this does little to stifle the need for surrogate decision-making. This is because ACP can establish ceilings of care fairly well, but...
there are potentially infinite decisions in between admission and a ceiling of care that must be navigated. ACP is not well suited to address these, certainly not outside of the confines of a particular disease or current plan of care. That is, it is virtually impossible for someone to establish ACP in such a way that accounts for all future care. This is important, because it points to the reason why surrogate decision-making will always be a necessary and integral part of health care. As such, it is vital that decisions that are made in a patient’s stead dignify them. And a framework that relies on a relational understanding of dignity, which itself sets standards of interpersonal conduct based on a person’s narrative understanding of themselves and their situation, is a significant step in improving this inherently fraught process and accomplishing this goal. It is my hope and objective that this project will contribute to the process of surrogate decision-making by providing an account of dignity that is able to support making dignifying decisions for the patient.

Narrative-based relational dignity can offer an underappreciated contribution with respect to navigation uncertainty and moral conflicts in the context of surrogate decision-making. This understanding of dignity requires that we work to discern the patient’s narrative, broadly construed, as best as possible. This entails moving beyond the facts-based approach we often see in case studies, toward a far richer understanding of the patient’s history, values, preferences, relationships, and social context—a claim further developed in chapter 5. Decisions made in the patient’s stead must fit with their narrative, because deciding otherwise would violate these key parts of their identity, and as a result would undignify, disrespect, or humiliate them. Decisions that support the patient’s narrative, on the other hand, dignify them as the full and equal persons that they are. They are the result of an understanding of the patient that is the result of the clinician’s proper uptake with the patient’s narrative. It is important to emphasize that this framework will improve upon the process of surrogate decision-making, without ultimately resolving their moral complexity and inherent fraughtness. Recognizing these complications does not mean it’s all awash. Rather, a framework that recognizes the uncertainty in the process that it is addressing, and that centers the patient and their narrative, makes for better, more inclusive and ethical surrogate decision-making.

D. Cases

Clinical ethics often proceeds by the process of discussing case studies, a format both familiar to philosophers and medical professionals. As a project in the area of clinical ethics, this dissertation is rich in case studies, both real and imagined. Given their centrality, it is worth providing the principal cases up front. In the following chapters, I discuss each of these cases repeatedly, using them to extricate central features of the views under discussion, and demonstrate the strengths and weaknesses of these accounts in their ability to come to terms with these cases. In chapter 5, I challenge this traditional case format, which is rooted in both philosophical thought experiments and the medical case composition. I intend to show that this conventional case presentation constitutes a barrier to the implementation of the framework for decision-making developed in this project.

**Case—Trading Dignities**

A terrorist organization has placed Improvised Explosive Devices (IEDs) throughout a major U.S. city. The detonation of these devices would likely kill hundreds if not thousands of people, and injure many more. Counter-terrorism agencies have been unable to locate the devices, but they know they will detonate within a few hours. This does not leave enough time to evacuate the city. They have captured a member of the terrorist organization, who they have good reason to believe has knowledge of the IED-placement. The operative counter-terrorism team is considering their options, but time is running out and without any new leads, it seems unlikely they will be able to track down the IEDs in time. They are considering as their last resort to torture the suspect in the hopes of extracting information that can save the city.

**Case—Capacity for Preferences**

[The patient is a] Forty-one-year old male who at age twenty-five had been involved in a car accident that left him paralyzed from the waist down and with a traumatic brain injury ... He had a court-appointed guardian and had lived in group homes since becoming paralyzed ... He was admitted to the hospital for stage 4 decubitus ulcers on his legs resulting from lack of hygiene and refusal of wound care ... the patient consistently refused wound care ... [and] denied that he was paralyzed. [Treating physicians were considering three potential courses of action, namely] a six-week course of intravenous antibiotics [requiring] six weeks of prolonged restraint, amputation below the knee, or no curative action but comfort care in the hospital and then hospice once he became septic. (Quoted from Wasserman and Navin 2018, 33, 32)
**Case—Amputation or Death**

The patient is a seventy-two-year old man without known friends or family, who suffers from hypertension, diabetes mellitus, peripheral vascular disease, and schizophrenia. He has been admitted with four necrotic toes. When he was previously admitted with a similar problem on his other foot, the physician and ethics committee jointly decided on a below-the-knee amputation (BKA). The patient consented on the condition that he would be provided a prosthetic leg. It was reasonably expected that he would be able to receive this. However, he was never fitted with a prosthetic leg, likely due to effects resulting from his mental illness. Given his current condition, preventing the spread of gangrene up the foot and leg would require amputation. The degree of damage cannot be determined pre-op, which means that amputation could range from removing just the toes, all the way to an above-the-knee amputation (AKA). Alternatively, the patient could be provided with a comfort-focused plan of care without amputation. This would likely result in sepsis and ultimately death. (UTMC Ethics Committee 2018)

**Case—(How) Do We Choose Our End?**

The patient is a 46 year old female patient. She came in “feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. They did a bone-marrow biopsy and she was diagnosed with acute myelomonocytic leukemia. The oncologist proposed a course of induction chemotherapy, followed by consolidation chemotherapy, and finally a bone-marrow transplant. The survival rate of this course of treatment is about 25%. The survival rate of no treatment is about 0%. The oncologist met with the patient to inform her of the diagnosis and had made plans to begin induction chemotherapy that afternoon. This enraged the patient, who refused treatment. When the patient saw their treating physician several days later, they remained steadfast in their refusal for treatment, with limited support from their family. A couple of weeks later, the patient came to the physician requesting barbiturates to aid in sleep. While barbiturates can be a powerful sleep aid, their non-prescription use can also result in death. In conversation with the patient is becomes clear that they are planning to use it as a sleep aid, but that they are also aware of its secondary use, and wish to have enough of the medication to be able to commit suicide. By law, the physician is banned from providing assistance in patient suicide. The physician must choose whether or not to assist the patient. (Originally from Quill 1991a)
Case—Going Home to Dolly

Mary Beth is a 68 year old female patient who was hospitalized after a fall in her own home. She was down for at least a full day before EMTs found her after a call by a concerned neighbor. After several days in the hospital Mary Beth is making a decent recovery, but it’s not clear that she can live on her own. She has limited mobility, is at a high risk of falling and injury, and she is showing early signs of dementia. When asked what her plans are after discharge, she explains that she’ll go back home. When asked about help inside the home, she explains that she knows Dolly Parton quite well, and Dolly will be checking in on her regularly. It is clear from extended conversations and evaluation that she is saying this in earnest. After checking with neighbors, it is clear that Mary Beth has no personal relationship with the country music icon, and that she is confabulating about her post-discharge situation.

Case—Dax Cowart and Paternalism in the Burn Unit

In 1973, 25-year-old Dax Cowart, former captain of his high school football team, former Air Force pilot, rodeo rider, and aspiring commercial pilot, was severely burned as a result of a freak accident. Dax’s father had inadvertently parked his car on a bridge over a leaking propane pipe, and a spark from an attempt to start the car caused an explosion. His father was killed and Dax suffered a burn to 65% of his total body surface area (TBSA), with third-degree burns to his face, ears, and hands. Most of his fingers were amputated and he lost vision in both eyes. His words to the first person, a farmer, who arrived at the scene were, “Get me a gun. Can’t you see I’m a dead man. I’m going to die anyway.” During his very painful 14 months of treatment—6 in the hospital and 8 in a rehabilitation facility—Dax repeatedly requested that the team discontinue treatment. He asserted that he did not want to live “as a blind and crippled person” and demanded that he be permitted to die even though his mother was consenting to treatment. According to Dax, his physicians generally ignored these requests even after he was deemed to have decision-making capacity by a respected psychiatrist. (Verbatim from Gerrek 2018, n.p.)

Case—Andrea Rubin and Surrogate Decision-Making in the Burn Unit

In 2014, Andrea Rubin was a 49-year-old health insurance sales representative. She had just started this job, having previously been employed in marketing and advertising, and was looking forward to her first busy season. One evening, as she was turning around in a parking lot, her car got stuck after a tire slipped off the pavement. As she tried to dislodge the car by alternating between drive and reverse, the motion caused a spark that set the car on fire. The inside of the car quickly filled with carbon monoxide and she lost consciousness. Andrea suffered a 58% TBSA burn
with third-degree burns to her face, ears, head, chest, arms, back, and legs. She suffered fourth-degree burns to her lower right arm, which was subsequently amputated just below the elbow. She also lost partial vision in her right eye. Her scalp was so badly burned that her hair will never regrow. Her father, like Dax's mother, consented to treatment. Yet, while Andrea was sedated for approximately two months to promote healing and could not participate in decision making, her friends repeatedly pleaded with the team to discontinue treatment and let her die. They were adamant that “she would not want to live this way” and that she would refuse treatment were she able to express herself. Given her father’s legal standing as her next-of-kin surrogate and his continued support of treatment, the pleas of Andrea's friends went unheeded. Andrea ultimately spent three months in the hospital and two months in rehabilitation and continues to seek outpatient treatment for her burn injuries. (Verbatim from Gerrek 2018 n.p.)

**Case—Mrs. Rogoff's Change of Heart?**

Mrs. Rogoff was always an independent woman. Raised in an immigrant family, she was used to working hard for what she wanted. Most of her life she ran a successful business selling liquor. She also developed local fame as an outstanding cook and hostess. After her third husband’s death she lived alone, enjoying what she considered, by old-country standards, a luxurious lifestyle: keeping up a nice big house and indulging in restful leisure. She was an introvert, always carefully guarding the way she presented herself to others. Life interested her insofar as she could live according to her own sense of comfort, making her own mistakes and relying on her own strength and wisdom.

In her early eighties Mrs. Rogoff developed severe motor impairments, which could only be corrected by a risky neurosurgery. She decided to undergo the procedure, insisting that she would rather die than be immobile. She prepared a living will, requesting not to have her life prolonged if she became a burden to her family or if she could no longer enjoy her current quality of life.

The surgery was successful, but shortly thereafter Mrs. Rogoff developed early signs of dementia: memory and word-finding difficulties. As she became more and more disoriented, her daughter hired a housekeeper, Fran, who moved in with Mrs. Rogoff. Fran takes care of Mrs. Rogoff the way one would take care of a child. Mrs. Rogoff enjoys the long hours she spends with Fran, and with her grandchildren whenever they visit, telling them somewhat disjointed stories about her earlier ventures. She watches TV a lot and her stories often incorporate the more exciting episodes from TV as if they pertained to her own life. In her more lucid moments, Mrs. Rogoff tells her grandchildren that she is scared to die, that “she doesn’t want to go anywhere.” She usually cries when Fran is away and when her grandchildren wrap up their visits.
Fran has to make day-to-day decisions for Mrs. Rogoff: Should Mrs. Rogoff get dressed if her family is coming to visit and she insists on wearing pajamas? Should she take a bath every day even if she is afraid of water? Should she be taken to fix her dentures, if every excursion out of the house makes her scared and unhappy? In general, should the current decisions reflect the care Mrs. Rogoff used to take in how she presented herself to others? Mrs. Rogoff’s daughter faces the more weighty decisions: Should she use up Mrs. Rogoff’s savings to pay Fran’s salary, allowing Mrs. Rogoff to keep enjoying her companion, or should she place Mrs. Rogoff in a nursing home, increasing the likelihood that, when the time comes, there will be some money left to execute Mrs. Rogoff’s will? What treatments should she authorize if Mrs. Rogoff develops a dangerous but treatable infection? (Verbatim from Jaworska 2005, 105-106).

E. Outline

Chapter 1 sets up the dignity landscape as it appears in applied ethics. It suggests that there are roughly ten different ways of understanding dignity, which can be divided into three primary categories, namely status dignity, universal dignity, and relational dignity. While all forms of dignity concern some kind of status—wherefore status dignity is the umbrella category—universal dignity and relational dignity are sufficiently manifest subcategories that they warrant distinction. In this chapter, I first set out the ten different conceptualizations of or perspectives on dignity along with some of their primary defenders. Second, I discuss competing approaches to the dignity landscape, by specifying the different ways dignity theorists have understood the categories of dignity. Third, I propose my own map of the dignity landscape, consisting in status dignity, universal dignity, and relational dignity. This map proposes status dignity as the overarching category, argues for the conceptual extraction of the latter two categories, and sets aside the remaining variants of status dignity. Third, I explicate Immanuel Kant’s account of dignity and its role in his ethical theory. Fourth, I use the Kantian account of dignity to develop a broader, universal account of dignity. I subsequently demonstrate that this conception of dignity is pervasive in clinical ethics. Finally, I discuss a number of problems that arise from this universal account of dignity, in particular in the context of clinical ethics. I also consider possible ways of addressing these, and how these strategies might fail. Ultimately, I argue that in order to maintain the concept of dignity and its vital role in clinical ethics, we stand in need of a different account of dignity.

Chapter 2 expounds upon and critically evaluates three relational views of dignity. In particular, this chapter looks at the accounts offered by David Luban, Suzy Killmister, and Linda Barclay. Each of these perspectives is evaluated in terms of its
strengths and weaknesses, both conceptually and with respect to an application in the context of healthcare.

Chapter 3 proposes a different theory of dignity, namely a narrative-based account of relational dignity. First, I introduce this conception of dignity in broad strokes, as one that locates dignity in the interaction between persons. Second, I offer a detailed account of the nature of narrative, which is the grounds for dignity. This includes a discussion of the various features that constitute one's dignity, how we should understand the term narrative, and an analysis of the relationship between narrative and literary theory. Third, I integrate this conception of narrative into a more detailed study of relational dignity. Fourth, I illustrate the practicability of the account by applying it to a series of key clinical ethics cases. Finally, I consider the extensionist potential of the account, by discussing narrative and dignity in the context of recently deceased people, as well as in relation to animals, and the environment.

Chapter 4 applies the narrative-based account of relational dignity to cases of surrogate decision-making, principally those concerning individuals who suffer from Alzheimer's disease. First, I analyze the nature of uncertainty in medical decision-making and what this means for the limits of dignity. Second, I discuss the practice of surrogate decision-making, the role of advance directives, and the unique problems surrogate decision-making poses for the patient's dignity. Third, I look at the debate on surrogate decision-making in the context of Alzheimer's disease. In particular, I evaluate the competing perspectives offered by Ronald Dworkin and Agnieszka Jaworska. I subsequently discuss the nature of narrative in relation to Alzheimer's disease, before analyzing the relevant case studies according to the narrative-based account of relational dignity. This accounts strengths in handling these notably challenging circumstances constitutes, I claim, a strong argument in favor of its authoritativeness as a framework in clinical ethics.

Chapter 5 offers a critique of the traditional case format. It demonstrates how this conventional way of presenting the data obscures relevant, narrative-based information. In order to make the narrative-based account of relational dignity practicable, we need to rethink case composition. I make the case for this in part by offering case presentations that contrast to the traditional format and emphasize narrative features.

The conclusion offers a summary of the benefits of narrative-based relational dignity over universal dignity and other relational views. It also looks forward to the future of this project, including the further development of the nature of narrative, what this account of narrative means for how we think about death, and how this framework of relational dignity may be implemented in a clinical setting.
CHAPTER 1: (Universal) Dignity in Philosophy

A. The Dignity Landscape

The dignity landscape is by no means sparse. Indeed, if any concept can be said to be ubiquitous in Western ethics, it is dignity. It is one of the keystone concepts in the Kantian tradition and foundational to Western liberalism. We find the term throughout the literature on metaethics, animal ethics, environmental ethics, human rights, global affairs, as well as medicine and clinical ethics. Given its ubiquity, we might think that there is significant agreement on what we mean by “dignity,” but nothing could be further from the truth. In fact, a significant portion of the recent (and not so recent) literature on dignity concerns this very issue: for all its pervasiveness, we seem to lack a consistent definition. The thicket of dignity-discourse can make any discussion on the subject unclear, in part because it seems that dignity suffers from heteronimity: the term names different albeit related concepts. We should therefore be careful not to equivocate. In light of this conceptually confusing landscape, it is useful to map it out, and locate the various views in it.

Moving from landscape to map is, of course, an imperfect exercise in translation. Fortunately, a lot of work has been done on taxonomizing dignity. While this is not an attempt at broadscale revisionism regarding the categories of dignity, I do want to carve out a space on the tree of dignity, where I can locate the view I’m arguing for in this project. To this end, it will be useful to consider an overview of the various taxa. Recognizing that there are many different ways to categorize the various ways of understanding dignity, I first briefly discuss ten different ways of conceptualizing dignity, before discussing how various authors have proposed to categorize subsets of these views. Here, I draw primarily from the perspectives of Doris Schroeder (2008), Suzy Killmister (2009, 2020a), and Michael Rosen (2018). Next, I offer my own interpretation of the landscape, made up of three categories, namely status dignity, universal dignity, and relational dignity. In the following section, these categories will be discussed in greater detail. This allows us to locate the positive view more accurately, and see how it relates to and differs from the other conceptualizations of dignity.

Ten Kinds of Dignity

1. Kantian Dignity will be treated at length later in this chapter. For the moment, Killmister’s summary of Kantian respect is sufficiently representative of this view. She notes that, for Kant, “what makes all persons worthy of respect is our capacity for a will that operates according to our own laws of reason” (Killmister 2009, 160).
2. **Divine Dignity** is the kind of dignity instilled in humans by God. Susan Haack, in “Human Dignity: A Brief Overview,” posits that dignity is related to the Christian notion of being created in the image of God and the “infinite significance” this has bestowed within us (Haack 2012, n.p.). According to Haack, this is the only conceptualization of dignity that is universal and equal (Haack 2012, n.p.). Moreover, this doesn’t merely entail that human beings have dignity, as it also requires that we should live lives of a certain kind, namely one that lives up to the standard of dignity. This means that “in the ambiguity and paradoxical nature of the term human dignity is located both the height of human excellence and the floor below which our respect should not fall” (Haack 2012, n.p.). Furthermore, research staff at the Center for Bioethics & Human Dignity, “a Christian bioethics research center,” suggest that “Human dignity is the recognition that human beings are worthy of a particular level of esteem or respect simply because they are human beings” and “Human dignity is the way of expressing the value of human beings. This stands in sharp contrast to the way in which we express the value of things: price” (CBHD n.d., n.p.; CBHD Research Staff 2006, n.p.). This opposition between dignity and price draws directly from the same contrast noted by Kant (Kant 2006/c. 1785, 42). CBHD diverges from Kant insofar as they specify that “Human dignity does not arise out of some ability or combination of abilities (i.e., autonomy, rational thought, self-awareness, freedom)” (CBHD 2006, n.p.). Instead, they agree with Haack, that “human dignity is an inherent aspect of being human, the result of being created in the image of God” (CBHD 2006, n.p.).

3. **Human dignity** is a phrase that is meant to indicate the use of dignity in the context of political liberalism. The famous example is the United Nations Universal Declaration of Human Rights, which recognizes “the inherent dignity and of the equal and inalienable rights of all members of the human family” (United Nations General Assembly 1948, n.p.). This use of dignity is often meant to gesture at some fundamental human value that must be respected, but generally does not provide the theoretical underpinnings that substantiate the value-claim. On the one hand, this supports its universal appeal, because it does not depend on accepting a particular cultural, religious, or ethical outlook. On the other hand, it might mean that it doesn’t have the substance to back up its claims. So while there is an attempt at increasing the universal appeal, insofar as it does not assume any particular outlook or theoretical background, there is reason to be concerned, because it’s silent on the foundational element that was, for good reason, explicit in the Kantian and divine conceptions of dignity.

4. **Aristocratic dignity** is the kind of dignity that was popular pre-industrialization, and associated with “secular or religious positions of high rank,” which often requires one to “act in accordance with” this position (Schroeder 2008, 233; referenced in
This is, in other words, the dignity that attaches itself to high
positions, such as that of priest, king, or empress.

5. **Type dignity** is the phrase I use to refer to, essentially, the modern version of
aristocratic dignity. It is the dignity associated with various kinds of positions and
roles. Judgeships are a clear example of a role that has norms attached to it that can
be expressed as dignity. But similar kinds of norms exist for other kinds of offices,
professions, and social positions. People are expected to stand for a judge, and fawn
over celebrities.

6. **Comportment dignity**. This is the kind of dignity that is manifest in the “outward
displays” of actions and behavior, often but not necessarily connected to social
position or rank (Schroeder 2008, 233, original italics; referenced in Killmister 2009,
161). So whereas, for instance, the office of President of the United States of America
has dignity attached to it, whoever fulfills the role of POTUS must also conduct
themselves appropriately to that role.

7. **Meritorious dignity** is a notion of dignity that comes out of the Aristotelian
tradition, even though “Aristotle did not mention dignity in *Nicomachean Ethics*”
(Schroder 2008, 234; referenced in Killmister 2009, 161). This type of dignity is merited
by those whose self-worth consists in their “possess[ion of] temperance, courage,
and justice and are guided by wisdom” (Schroder 2008, 235). In other words,
meritorious dignity is earned by one’s living up to their moral requirements.

8. **Story-based dignity** is the form of dignity proposed by David Luban (2005). This
view bases the standards for interpersonal action on the individual’s story, which is
grounded in their having a point of view. Actions that conform to the person’s story
are dignifying, whereas actions that fail to conform to their story are humiliating. This
account serves an important exegetical function in the next chapter, where it is
recounted and evaluated in detail.

9. **Norm-responsive dignity** is the form of dignity that comes out of the account
proposed by Killmister (2017, 2020a). It grounds dignity in the relevant personal and
social values that ought to be honored in interpersonal relationships. Killmister
understands dignity at its most basic as a “upholding of standards” (Killmister 2017,
2070, original italics). Killmister specifies three different kinds of dignity, namely
personal, social, and status dignity. Personal dignity is based on the norms to which
the individual holds themselves, whereas social dignity is based on the norms to
which the individual is held by the relevant community (Killmister 2020a, 4-5). Finally,
status dignity concerns “standards for how members are to be treated” (Killmister
2020a, 5). To uphold these norms dignifies the person (Killmister 2017, 2071). To fail to
uphold these norms is to potentially subject the individual to three different kinds of
damage to their dignity, in particular frustration, violation, and destruction (Killmister
2020a, 5). This view is recounted in detail in the next chapter.

10. Dignity skepticism consists of two views, both of which question the legitimacy
or pragmatic value of dignity as a concept in ethics. Dignity, on these views, is a
concept that is best avoided because it fails to provide sufficient grounds for moral
normativity. First, in the absence of a convincing secular account, some theorists
have become what I call dignity nihilists. This is not merely a skeptical position
regarding dignity due to conceptual incoherence or vagueness (see dignity
agnosticism below), but argues that dignity is pernicious. Ruth Macklin argues for
dignity nihilism in her “Dignity Is a Useless Concept” (2003). Her argument for
nihilism is in part motivated by the fact that dignity can be used to motivate both
sides of the death with dignity debate (Killmister 2009, 160, 162). Macklin argues that
“A close inspection of leading examples shows that appeals to dignity are either
vague restatements of other, more precise, notions or mere slogans that add
nothing to an understanding of the topic” (Macklin 2003, 1419).

Macklin cites the United Nations Universal Declaration of Human Rights as a
key text that fails to provide meaning to its usage of the term, as well as the Council
of Europe’s Convention for the Protection of Human Rights and Dignity (Macklin
2003, 1419). Moreover, Macklin argues that the debate concerning death with dignity
demonstrates that the term itself lacks distinction. It either just means respect for
autonomy, or if it’s meant to refer to anything else it’s meaning is too vague to be
useful (Macklin 2003, 1419). For Macklin, whatever value the concept of dignity adds
to clinical ethics can be maintained through other concepts, and its use is not worth
the confusion it sows. She concludes that, “Dignity is a useless concept in medical
ethics and can be eliminated without any loss of content” (Macklin 2003, 1420).

Macklin is joined in her jettisoning of dignity from the ethical dictionary by
Frans Josef Wetz, who stated that “dignity is an entry from the old-European grand
vocabulary, which not unlike drugs tricks the addict into believing in fantastic fake
Kuhse also rejects the usefulness of the concept, arguing that “the notion of human
dignity plays a very dubious role in contemporary bioethical discourse. .... [It] has a
tendency to stifle argument and debate and encourages the drawing of moral
boundaries in the wrong places” (Kuhse 2000, 74; quoted in Schroeder 2008, 231).

Dignity nihilism is by no means a new concept. Schroeder traces it all the way
back to Arthur Schopenhauer (2017/1785), who Rosen calls “the Ebenezer Scrooge of
nineteenth century philosophy,” and his depreciation of Kant’s understanding of
dignity (Rosen 2018, 1). In his On the Basis of Morality, Schopenhauer pulls no
punches in addressing Kant:
Only this expression ‘Human Dignity,’ once it was uttered by Kant, became the shibboleth of all perplexed and empty-headed moralists. For behind that imposing formula they concealed their lack, not to say, of a real ethical basis, but of any basis at all which was possessed of an intelligible meaning; supposing cleverly enough that their readers would be so pleased to see themselves invested with such a “dignity” that they would be quite satisfied.

(Schopenhauer 2017, 1698)

As Schroeder explains, for Schopenhauer, the term dignity has all the intelligibility of “an idea that cannot be thought such as the highest number or the largest space” (Schroeder 2008, 231-2). Rosen sees this skepticism fueled in contemporaneous philosophy, both directly by authors such as Mackline, but also indirectly, through the use of the term dignity as a “mere receptacle” for various kinds of values and commitments across a range of domains including philosophy, politics, and religion (Rosen 2018, 6).

Second, dignity agnosticism is a suspension of judgment concerning the metaphysical status or utility of dignity. There are various reasons why someone might be agnostic with respect to dignity. First, in light of the unsettled nature of the term, we may be hesitant to accept one account over another, and therefore suspend our judgment concerning the content of the term. Second, even if we do accept a particular characterization of dignity, we may then think that it is too closely tied to a particular moral outlook. If we don’t want our moral discussion to require a particular moral theory, then this conceptualization of dignity is best avoided. Third, even if we accept a particular account of dignity and its requisite moral outlook, we may find that the concept is insufficiently action guiding, and so does not serve a practical role in applied ethics. Fourth, we may find that other terms do the heavy ethical lifting more easily. Someone who is raising these questions may not conclude that dignity is altogether useless or empty, nor think that the concept is pernicious, but may ultimately suspend judgment and prefer to prioritize other concepts in their ethical outlook.

Dignity theorists who offer positive accounts have generally set aside or argued against dignity skepticism (Schroeder 2008; Killmister 2009). For this, and the reasons noted above, I join them in leaving the skeptical outlooks off the map from here on out. Each of the views above admit of the potential for subviews, and I do not claim that this list is exhaustive. Nevertheless, I believe I have succeeded in offering a sufficiently detailed overview of the main features that mark the dignity landscape. The account I’m proposing draws from several of the other views set out above, primarily story-based dignity and norm-responsive dignity. Nevertheless, compared to some of the other, more traditional views of dignity—in particular Kantian dignity and divine dignity—it can rightfully be considered highly revisionist, as it attempts to preserve an important moral concept by giving it a different philosophical
foundation. In short, I propose an eleventh kind of dignity, that is not easily reduced
to any one of the other kinds discussed above.

Surveying the Dignity Landscape

There are many different ways of mapping out the dignity landscape, and those who
seek to unify various conceptions of dignity into taxonomic classes have also
recognized different types of dignity or have suggested different names for certain
kinds. For this reason, and in order to keep this discussion concise, I focus on the
different classification offered by Suzy Killmister (2009, 2020a), and Michael Rosen
(2018). I also briefly take note of the categorization of dignity offered by David Luban
(2005), because his account features prominently in the next chapter and serves as a
stepping stone for Killmister's more developed scheme.

Luban divides the landscape into two main categories, namely broadly
Kantian views of dignity, which understand dignity as a metaphysical quality, and his
own relational account, which avoids those mysterious metaphysical underpinnings.
Luban cites Oscar Schachter's discussion of dignity from his "Human Dignity as a
Normative Concept" (1983). Schachter, reflecting on the phrase "dignity and worth of
the human person" used in human rights documents, suggests that dignity and
worth are synonyms" (Luban 2005, 839, quoting Schachter 1983, 849, supra note 6).
Luban disagrees, and argues that this notion of dignity as "intrinsic worth" only
constitutes one particular use of dignity (Luban 2005, 839). Instead, Luban connects
dignity to rank or status, where “an indignity occurs when someone is treated below
their rank” (Luban 2005, 839). With respect to human dignity, Luban understands
this to “refer to the prestige conferred simply by being human,” and “To violate
someone's human dignity means to treat them as if they were a being of lower rank”
(Luban 2005, 839). This distinction between Kantian accounts on the one hand, and
alternative conceptions on the other, is a consistent feature across this survey.

In her earlier work, Killmister simplifies Schroeder’s account, which offers four
main conceptualizations of dignity, namely Kantian dignity, aristocratic dignity,
comportment dignity, and meritorious dignity (Schroeder 2008, 233-5). Each of these
has been defined in the previous section in accordance with her account. Killmister
creates a primary contrast between the Kantian sense of dignity and what she calls
“the aspirational sense” of dignity (Killmister 2009, 161). This latter sense of dignity
merges comportment dignity and meritorious dignity, and is expressed by personal
or social norms that the individual should live up to (Killmister 2017, 161, 2072-4). She
leaves out aristocratic dignity, because it's a dated concept with little contemporary
relevance (Killmister 2009, 161).

In her recent Contours of Dignity (2020a), Killmister reverts to a more
fine-grained categorization of dignity. She refers to the Kantian view as “dignity as
inner worth” (Killmister 2020a, 6). This is contrasted with three other views. First is
“dignity as elevated status” (Killmister 2020a, 9). This category understands dignity as conferred, multitudinous, and vulnerable (Killmister 2020a 10). Second, “dignity as admirable quality” (Killmister 2020a, 11). This combines many of the features of Schoeder’s non-Kantian categories, understanding dignity as conferred, and variable (Killmister 2020a, 12). Third, “dignity as respectful treatment” where dignity is “a quality that inheres in the relationships between people” (Killmister 2020a, 12). Here, too, dignity is conferred, and vulnerable (Killmister 2020a, 13). Ultimately, Killmister’s own view on dignity is aspirational in the sense that it concerns personal and social norms that we ought to live up to, which makes dignity conferred and vulnerable (Killmister 2020a, 5).

Michael Rosen, in his aptly titled *Dignity: Its History and Meaning* (2018), discusses the history and meaning of the term dignity. Rosen sees the history of dignity as consisting in various strands, running from Cicero during the first century BCE onward, “that come together and move apart at different times” (Rosen 2018, 2-4, 8). He initially identifies three primary and distinct conceptualizations of dignity, adding his own as the fourth. The first category of dignity is that of dignity as universal and inherent value (Rosen 2018, 6, 54). This refers both to the Kantian account of dignity as well as the kind of dignity found in liberal manifestos, such as the Universal Declaration of Human Rights (Rosen 2018, 6). The second is dignity as status, where dignity concerns one’s social status (Rosen 2018, 54-5). This includes hierarchical views of status, such as in the case of Pope Leo XIII’s insistence that a person’s dignity “consists in their playing the role that is appropriate to their station within a hierarchical social order” (Rosen 2018, 48-49, referencing Pope Leo XIII 1878, 6). It also includes egalitarian views, on which “there are no intrinsic status differences” between human beings (Rosen 2018, 55). And third, there is “dignity as behavior, character, or bearing that is dignified” (Rosen 2018, 54). Here dignity might refer to “An aesthetic quality that manifests itself in human behavior or … virtue” (Rosen 2018, 6). Or it may “denote the bearing required by differentiated status hierarchy,” which Rosen sees in authors like De Tocqueville and Aquinas (Rosen 2018, 47-8).

Finally, Rosen puts forth a fourth category of dignity, “in which the idea of dignity as the dignified should figure within the comprehension of dignity.” (Rosen 2018, 57). Rosen relates this view to that of Joel Feinberg, who argued that “what is called ‘human dignity’ may simply be the recognizable capacity to assert [rights] claims” (Rosen 2018, 5, 57, quoting Feinberg 1980, 151). Rosen traces this idea back to the Geneva Conventions (1949), which he argues provide different content to the notion of dignity than, say, the Universal Declaration of Human Rights (Rosen 2018, 58-60). In particular, the Geneva Conventions ratified a universal right to “dignified treatment” and “should not be treated disrespectfully by being humiliated or degraded” (Rosen 2018, 60). On Rosen’s account of dignity, respect does not directly respond to a “set of fundamental rights,” but rather “requires respectfulness” such...
that “to have one’s dignity respected is one particular right … rather than something that acts as the foundation for rights in general” (Rosen 2018 61-2).

This notion is, of course, broadly Kantian (Rosen 2018, 60-1). Rosen nevertheless goes through great lengths distinguishing his views from Kant’s framework. He argues for a reading of Kant on which what makes humans special is their participation in the noumenal realm. It is this fact that imbues us with value, and it is this value, not our humanity, that is the grounds of dignity (Rosen 2018, 155). Rosen argues that this makes Kant anti-humanistic, because respecting dignity does not necessarily promote the good of humans; rather, it is appropriate to this fundamental value. One key problem that follows from this, is that there is no clear way to rationally move from this unaffected value to actions that are appropriate to it (Rosen 2018, 155). This is where Rosen draws a sharp contrast with Kant, stating “Dignity in the sense of being treated with respect for one’s humanity is not the fundamental ground of human rights that the Kantian (or Catholic) use of the term would imply. Suffering, to my mind, is bad, and love good, in themselves, not, as Kantianism implies, because of their relationship to something else” (Rosen 2018, 157). Here, Rosen moves dignity out from the roots of morality to its branches. It does not explain or provide the grounds for value, as it does for Kant, but it does create standards for action, grounded in “the value of human beings” (Rosen 2018, 160).

**Mapping the Dignity Landscape**

I propose that the dignity landscape, at least for the purposes of this project, is best understood as divided into three primary categories. These main categories are status dignity, universal dignity, and relational dignity.

**Status dignity** is the umbrella category. All dignity concerns status of some kind, whether this is the status of having intrinsic worth (Kantian dignity, divine dignity, and the intent of human dignity), the status associated with a particular rank or type (technically human dignity, aristocratic dignity, type dignity, and comportment dignity), the status entailed by achievement (meritorious dignity), the status of having a perspective (story-based dignity), or the status of having personal or social norms (norm-responsive dignity). All status dignity is normative, insofar as it concerns standards, but it can be both morally normative (Kantian dignity, divine dignity, human dignity, Aristotelian meritorious dignity, story-based dignity, and norm-responsive dignity) and non-normative (aristocratic dignity, type dignity, comportment dignity, and general meritorious dignity). Status dignity can also be expressed in terms of being a good of a kind, where the standard of goodness can be socially, culturally, or naturally determined. This holds across the different kinds of dignity, where this may require being a good biological human (kantian dignity, divine dignity, human dignity, Aristotelian meritorious dignity, story-based dignity),
empress, judge, or celebrity (aristocratic dignity, type dignity, comportment dignity), or bearer of norms (norm-responsive dignity).

My aim is to extract two categories from this overarching conception of dignity, namely universal dignity and relational dignity. While status dignity is the overarching category, in the context of this project I mean for status dignity to refer to the set of views outside of universal dignity and relational dignity. Status dignity involves meeting certain kinds of standards, whether moral or not, which can generally be expressed in terms of being a good of a kind: from a good rational agent, to being a good judge, to being a good socialite. Extricating universal dignity and relational dignity from the conceptual fray befits the literature and allows for a more focused discussion and development of these views.

**Universal dignity** includes Kantian dignity, divine dignity, and human dignity. As a subcategory of status dignity, these views concern in particular moral status. The unifying feature of universal accounts of dignity is that the function of dignity is to define a single foundation or common trait in virtue of which each human deserves moral treatment. This could be a particular capacity, being created in the image of God, or membership in the species or social system. Universal dignity is the predominant philosophical conception of dignity. It is broadly Kantian, and refers to the moral status human beings enjoy in virtue of being (rational) human beings. Dignity is generally tied back to some human capacity—in Kant’s case rationality. There are potential problems here. Not all humans are rational, and even if we ground dignity in some other capacity, it remains true for virtually all capacities that not all humans possess it. All humans are humans, but it’s not clear why humans would be a moral rather than merely a biological category. In other words, the trait of humanity is itself a kind of stand-in for particular capacities, any one of which might escape the individual. So universal dignity might have conceptual trouble realizing its universality. Even if we accept its universality, universal dignity is not in every case a helpful conceptual tool in moral decision-making. While it can help us explain why torture and murder are always wrong, outside of universal wrongs it has a more difficult time navigating moral conflicts. Alternatively, if we deny the existence of universal dignity, then we need some other framework for showing why torture and murder are wrong. Given that it is not a far stretch of the imagination that a different framework of dignity can accomplish this, we are left on equal footing with respect to the demand to navigate more nuanced moral conflicts.

Another popular conception of universal dignity comes out of political philosophy and the human rights discourse. The claim here seems to be that all human beings have dignity, whatever it is, and that this entails both positive and negative duties on the part of the state to protect and respect it. It may be that the kind of status this view is concerned with, is that of citizen or subject. That is, dignity
derives from the existence of political entities and extends to those who are
governed by those entities. Human dignity, then, becomes about political status.

As we have seen, one popular kind of discourse concerning dignity that is
relevant here concerns the debate concerning death with dignity. There is a
significant philosophical and popular literature on death with dignity. Those who
oppose physician assisted suicide and active euthanasia often argue against the
moral permissibility of MAID by appealing to the universal dignity of human beings.
This dignity constitutes our inherent worth and is such that it ought not be
deliberately destroyed. However, those in favor of expanding MAID also frequently
appeal to dignity. It would be borderline incoherent to equate this type of dignity
with universal dignity, since the very act of bringing about death destroys universal
dignity. Here, death with dignity seems to suggest a pathway toward death that
coheres with the values of the individual and their community and that begets as
little undignifying treatment as possible. Universal dignity is unable to
straightforwardly account for this popular usage.

In short, universal dignity has important conceptual challenges, but even
outside of those, it offers little help in navigating the kinds of practical moral conflicts
we often encounter in applied ethics in general, and in particular in the context of
clinical ethics. These claims are further developed in the remaining sections of this
chapter. It’s important to emphasize that I’m not denying that each person has
inherent moral worth, and that the framework I’m advocating for as part of the
narrative-based relational account of dignity can and should be accepted by many
people who hold some version of the universal account of dignity. So while I develop
this view in part in contrast to universal dignity, I am not necessarily attempting to
argue anyone out of holding such a view.

Relational dignity includes story-based dignity and norm-responsive dignity. Like
the universal accounts dignity, these relational accounts are all morally normative.
Unlike the universal accounts, they deny the metaphysical roots of dignity. The
unifying features of relational accounts of dignity is that dignity is best described as a
success term in evaluating interpersonal actions. An appropriate response to the
person’s story or norms is dignifying, and an inappropriate response undignifying.

In the next chapter, I discuss the relational accounts of David Luban (2005),
Suzy Killmister (2010-2020a), and Linda Barclay (2016, 2018). While I categorize their
views as relational ones, they might resist this move. Luban (2005, 839) and Barclay
(2018, 63) explicitly taxonomize their accounts as status dignity ones. Though
Killmister initially refers to her view as one of aspirational dignity, Barclay suggests
that Killmister’s account “is best understood as an account of dignity as bearing”
(Killmister 2009, 161; Barclay 2018, 64). Later, Killmister resists categorizing her view,
other than contrasting it to “inherent worth” views and expressing her view as one of
conferred dignity (Killmister 2020a, 6, 5). Nevertheless, these views share the
important aforementioned features in common, which justifies their being joined together under a singular category.

The conceptualization of dignity that I’m after attempts to identify a central feature of our personhood, namely our narrative, that must be appropriately responded to in our interpersonal actions. This is the narrative-based account of relational dignity. The aim is for this theory of dignity to develop into a framework for surrogate decision-making. What this view shares in common with the universal accounts of dignity, is that it is in virtue of a single feature—in this case our narrative—that each person has the potential for dignity. However, for these other views the relevant feature is itself singular—such as membership in the species, being a rational agent, being made in the image of god. The relational view, by contrast, is highly pluralistic. “Narrative” is a holonym that consists of various potential meronyms. This means that different people may deserve dignifying treatment based on distinct narrative elements. For instance, a fully capacitated adult human being may deserve this based on the full set of narrative features. Someone who is brain dead and without family may deserve this based on their membership in the global human community. And someone who lacks rational capacities but is highly emotive because they are autistic or have advanced Alzheimer’s disease may warrant this based on their non-cognitive attitudes. I develop this account of narrative and dignity in detail in chapter 3, and discuss its application to Alzheimer’s cases in chapter 4. Another potential difference is in the purposefully anthropocentric nature of the universal accounts. While this project is focused on dignity in humans, this is an artifact of the focus on clinical ethics. While I lack the space here to extend the account, I briefly take up with this possibility at the end of chapter 3.

Kant, Luban, Killmister, and myself—we’re all interested in a particular kind of status dignity, namely the status in virtue of which someone has moral worth. Indeed, Kant’s universal conception of dignity is a kind of status dignity, because it is predicated on having a particular kind of status, namely that of a rational, autonomous agent. Kant’s view is very important here, because (1) it is, whether implicitly or explicitly, incredibly influential in clinical bioethics, and (2) underscores the centrality of rational capacities in moral thought. As a particular kind of status dignity, it underscores the significance of the status of rational agent. This is vital in drawing out the contrast between universal dignity and the relational view I’m proposing. Our understanding of dignity is profoundly influenced by deontology, and by Kant in particular. We can acknowledge this contribution, while at the same time recognize that the universal account of dignity has difficulty ensuring respect and justice for the most vulnerable individuals and populations. As noted above, while the relational view of dignity can be understood as a status dignity view on which the relevant kind of status is that of being with a narrative, the notion of narrative constitutes a cluster of features such that there is not one feature that is definitive of
dignity. As this view emphasizes the relational nature of dignity, the term becomes less one of status, and more of a success condition in interpersonal relationships. In short, I’m proposing a substantively different, revisionist notion of dignity, which has as its background the Kantian view and its bioethical derivatives. To see the contrast most sharply, we first need to look in greater details at Kant’s notion of dignity. I subsequently develop a more general account of universal dignity. This will be used to evaluate how universal dignity shows up in clinical ethics, and serves as a contrasting account of dignity for the remainder of the project.

B. Dignity in Kant

Kant and the Universality of Morality

The hard problem in philosophy of mind refers to the nature of consciousness, i.e. how is it that experience exists in the material universe? One of the hard problems in metaethics is the question of moral status, i.e. how is that humans have moral status? In the eighteenth century, Immanuel Kant offered us a possible explanation: reason. In his *Prolegomena to Any Future Metaphysics*, Kant points to Hume as the source of his philosophical discontent (Kant 2001a/1783, 5). Hume's arguments for skepticism focuses on our fundamental understanding of cause and effect. In “Kant and Hume on Causality,” Graciela De Pierris and Michael Friedman note that Kant recognizes that Hume has uncovered a “general problem ... common to all the categories and principles of the understanding,” and this surely includes the metaphysics of morals (De Pierris and Friedman 2018, n.p.). Hume left the philosophical landscape in disarray, demonstrating that while empiricism had its practical uses, it could ultimately only justify skepticism and non-cognitivism. This left Kant with the challenge of establishing a plausible metaphysics and developing principles of morality. In order to avoid empirical principles that would ultimately lapse back into skepticism, Kant had to eschew empiricism in favor of rationalist, *a priori* principles. He develops this framework in his *Groundwork for the Metaphysics*.

2 In particular in the development of his metaphysics of morals, Kant also had to contrast his view with the empirical features of Aristotle, in order to establish his own work as more secure. For Aristotle, virtuous action realizes our end of living a life according to reason. The deeper distinction is that for Aristotle, what constitutes the morally good, *eudaimonic* life is determined, in the case of humans, through anthropology. Aristotle’s entire aim is to break with Plato’s realism/idealism and offer a more naturalistic account of virtue and morality. One of Kant’s aims in establishing a moral philosophy, is to establish moral laws that are free from the influence of experience. In Kant’s words, this framework for ethics must be “completely cleansed of everything that may be only empirical and that belongs to anthropology” (Kant 2006, 2). Kant’s motivation is clear: if moral requirements are to have any force at all, and not be the subject of endless exceptions, then they must be universal. And something can only be universal if it is necessary. Hence, morality must be anchored by *a priori* principles (Kant ...
of Morals (2006/c. 1785). What follows is a general overview of Kant’s moral theory, in particular as it’s relevant to his conception of dignity. Let’s center our discussion of Kant on a case that can help draw out the central features of the view.

Case—Trading Dignities

A terrorist organization has placed Improvised Explosive Devices (IEDs) throughout a major U.S. city. The detonation of these devices would likely kill hundreds if not thousands of people, and injure many more. Counter-terrorism agencies have been unable to locate the devices, but they know they will detonate within a few hours. This does not leave enough time to evacuate the city. They have captured a member of the terrorist organization, who they have good reason to believe has knowledge of the IED-placement. The operative counter-terrorism team is considering their options, but time is running out and without any new leads, it seems unlikely they will be able to track down the IEDs in time. They are considering as their last resort to torture the suspect in the hopes of extracting information that can save the city.

Kant argues that for morality to have any force, it must be universal. Consider our case Trading Dignities. Let’s say we are generally convinced that torturing a person is wrong. However, we are swayed by the details of this case, in particular the enormous potential loss of innocent lives. We determine, then, that torturing the suspect is justified in this instance. From there, we have grounds for an exception in sufficiently similar looking cases. Of course some of the facts may vary. Perhaps there are fewer potential victims. Perhaps we are unsure that the suspect possesses the relevant information, or that they are a member of the terrorist organization at all. We may quickly find ourselves sliding down the slippery slope toward a much more general application of torture. This is why, for Kant, a rule with exceptions is as good as no rule at all.

In order to follow rules, we need to know their content. Kant argues that through the exercise of pure reason we are able to ascertain the universal moral law, which then allows us to act as the moral law demands. More specifically, our capacity for reason allows us to inductively arrive at moral laws by considering hypothetical

2006, 2). For Kant, following rationalists like Descartes, we gain access to the a priori through the exercise of “pure reason” (Kant 2006, 3). So while both Aristotle and Kant arrive at the superiority of reason as the relevant capacity in ethics, Aristotle gets there by considering the characteristic activity of human beings (anthropology by definition), and Kant gets there because pure reason is our only access to the a priori, universal, necessary laws of morality.
rules, or maxims, that inform particular actions.\textsuperscript{3} From the particular, to the universal. Ultimately, Kant argues that there is only one universal law, what he calls the categorical imperative, that is the foundation of ethics. All other, more particular moral laws are just applications of this general, universal principle. Kant actually offers three versions of this one general “principle of morality,” which he claims are “only so many formulae of the very same law” (Kant 2006, 43). The three formulations are as follows:\textsuperscript{4}

1. “act only in accordance with that maxim through which you can at the same time will that it become a universal law” (Kant 2006, 31, italics removed);
2. “act that you use humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means” (Kant 2006, 38, italics removed), and;
3. “act in accordance with the maxims of a member giving universal laws for a merely possible kingdom of ends” (Kant 2006, 46).

For Kant, our actions must cohere with the possibility of all rational creatures acting in the same way under similar enough circumstances. This is, after all, what it would mean in practice for our action to be guided by a universal rule. We can check the possibility and desirability of this, by formulating a hypothetical rule of action and universalizing it. This is how we can deliberate about the rightness of potential actions. Ultimately, however, these minor moral imperatives are modes of the categorical imperative.\textsuperscript{5}

\textsuperscript{3} For Kant, decision making is about imperatives. In general, these take the form “if I desire to meet goal x, then I must y.” The form of this hypothetical imperative demonstrates that we can satisfy the imperative in two ways, namely by making good on its consequent or by abandoning the antecedent. We can avail ourselves of either one of these options, depending on the strength of our desire for x, the demands of y, and any other relevant variables. We can use our capacity for reason to consider and weigh these variables, and issue a judgment concerning the imperative. Things look rather different for moral matters. Here, the imperatives are not hypothetical. Instead, they take the form of rules. This means there is no opportunity to abandon the antecedent. There is only the rule that dictates how we ought to act, and this rule is universal. Unlike hypothetical imperatives, these are not contingent, means-ends relationships of mere “practical necessity,” but universal imperatives whose end is inherently good (Kant 2006, 25, 27).

\textsuperscript{4} Whether the three formulations in fact express the same rule is a matter of debate. Nevertheless, Kant suggests that each of the formulations focus on a particular intuitive aspect of the categorical imperative, namely its “form,” “matter,” and “complete determination” (Kant 2006, 43-44). Here, its form concerns its universality, and is expressed by the Formulation of Universal Law (#1). Its matter concerns its end, and is expressed by the Formulation of Humanity (#2). And its complete determination refers to the harmony between all laws in a kingdom of ends, where these laws are willed universally by all members in a way that coheres with the laws of nature, expressed in the Formulation of Kingdom of Ends (#3) (Kant 2006, 43-44).

\textsuperscript{5} I’m using “modes” here as roughly analogous to Spinoza’s use.
The Moral Law and Dignity

How does the universality of morality get us to dignity? Kant is ultimately a constructivist and holds that the moral rules derive from human reason. This is why it would be irrational not to act in accordance with the dictates of morality. Kant describes our construction of moral rules through reason as a kind of co-legislation, where ideal versions of all rational beings work together to generate a universal set of moral rules. Ideally, we all legislate these rules perfectly and follow them purely from our will to do good. Kant calls this the ideal, successful accomplishment of this moral cohabitation the Kingdom of Ends. To emphasize the universal nature of these laws, Kant emphasizes that “we cannot dispute that its law is so extensive in its import that it must hold not only for human beings but for all rational beings as such, not merely under contingent conditions and with exceptions but with absolute necessity” (Kant 2006, 20, original italics). This means that it is rationality itself that (1) provides access to moral laws, and (2) demonstrates their necessity. Kant argues that the capacity for generating these laws, namely the capacity for reason, and by extension those beings that contain this capacity, are the source of moral value, and must themselves be inherently valuable. It has what Kant calls “dignity” or Würde (Kant 2011/c. 1785, 98). He contrasts dignity with price, as the latter is by definition subject to exchange and so has extrinsic value, and notes that dignity “has not merely a relative worth, that is, a price, but an inner worth” (Kant 2006, 42). On this interpretation of Kant, our rational capacities generate the moral laws. Since the moral laws have value, as co-legislators we must also value, i.e. dignity. Alternatively, we may interpret Kant as maintaining that the moral law is itself primary. On this view, the moral law is a set or system of moral principles, under which each person

---

6 Moral rules are universal, and our will functions so as to align our action with these rules (Kant 2006, 24). Ideally, then, we are motivated to act according to the moral law by our good will. In acting out of respect for the moral law, we reach beyond the contingent, into the necessary, universal, and *a priori*. Kant expresses this in his three propositions of morality:

1. For an action to have genuine moral worth it must be done from duty (implicit in (Kant 2006, 12));
2. “an action from duty has its moral worth not in the purpose to be attained by it but in the maxim in accordance with which it is decided upon” (Kant 2006, 13), and;
3. “a consequence of the two preceding, I would express as follows: duty is the necessity of an action from respect for law” (Kant 2006, 13).

Failing this requirement means that the action has no moral value. Here, Kant is a close observer of the human condition in all its complexity, variability, and contradiction and notes that realistically, we rarely if ever act exclusively out of the will to do good (Kant 2006, 19-20). Strikingly, then, Kant does not care all that much about our motivation or moral contentment, because he sees this as self-congratulatory vanity. His account does not (often) allow us to pat ourselves on the back in appreciation of our worthy conduct. Rather, as long as reason reveals to us the moral law and we act accordingly, it doesn't much matter whether or not this brings about feelings of contentment or accomplishment.
enjoys equal status, i.e. dignity.

For Kant, dignity is about this capacity for reason whereby we can legislate moral rules and act according to them. This ability instills in us a unique kind of value or status, that limits the permissibility of actions towards others. It sets those with rational capacities apart from all other things as being priceless: “In the kingdom of ends [Reiche der Zwecke, (Kant 2011, 96)] everything has either a price or a dignity. What has a price can be replaced by something else as its equivalent; what on the other hand is raised above all price and therefore admits of no equivalent has a dignity [Würde, (Kant 2011, 96)]” (Kant 42, original italics).

Kant refers to the correct attitudinal response a rational being should have toward this dignity as “respect.” The original German term Kant uses for “respect” is “Achtung” (Kant 2011, 100). This is also commonly used to communicate that something must be watched out for, or heeded, and it seems that this is instructive in how Kant thinks about the nature of dignity. We must heed it, because the dignity of ourselves and others is the ultimate limiter of our actions. Indeed, “rational beings are called persons because their nature already marks them out as an end in itself, that is, as something that may not be used merely as a means, and hence so far limits all choice (and is an object of respect)” (Kant 37, original italics). As such the categorical imperative implores us to always respect those with dignity, by treating them as an end in themselves. Autonomy, by extension, is our capacity to act in accordance with our will. It is, as Kant describes, the consequence of “the presupposition of the freedom of the will” (Kant 2006, 64). The capacity for reason doesn’t merely allow us to be co-legislators in the kingdom of ends, it also enables us to act according to the law we help legislate for one another.

Relating this back to our case Trading Dignities, we now arrive at the eponymous issue. We can see that torturing someone for information is likely a clear violation of this expression of the categorical imperative. It entirely reduces someone to a mere means, to an instrument for obtaining information. And this, for Kant, is

---

7 It’s interesting to note that Kant does not limit his constructivism to human beings. Rather, it is tied to rationality itself, no matter how it arises in, or perhaps outside of, nature. He states that “For the purpose of achieving this it is of the utmost importance to take warning that we must not let ourselves think of wanting to derive the reality of this principle from the special property of human nature. For, duty is to be practical unconditional necessity of action and it must therefore hold for all rational beings (to which alone an imperative can apply at all) and only because of this be also a law for all human wills” (Kant 2006, 34).

8 Kant starts from the assumption that “All human beings think of themselves as having free will” (Kant 2006, 59). To conceive of ourselves as free is so fundamental to our humanity, Kant supposes, that we must assume that no true contradiction will be found between freedom and natural necessity in the very same human actions, for it cannot give up the concept of nature any more than that of freedom” (Kant 2006, 60). Reason is key to this freedom, as this is the part of ourselves that regard itself as free and formulate laws of action (Kant 2006, 54). Autonomy, then, is that part of our will that can issue volitions that accord with the moral law (Kant 2006, 47).
always impermissible. It does not matter how many lives we put on the other side of
the scale; how many flames of dignity stand to be extinguished. We may never blow
out that flame ourselves.\(^9\)

While moral laws are not dependent on any one particular reasoner’s capacity
for arriving at them through reason, they also do not exist independently of human
reason. For Kant, humanity as a community of reasoners co-create these laws by
arriving at their necessity through reason. No reason, no moral law. So at the same
time that our capacity for reason opens up the moral universe to us, it also initiates
us as one of these co-legislators of the moral law. This is why Kant understands
morality to be synthetic \textit{a priori}. We discover (synthetic) the necessity and
universality \textit{(a priori)} of morality through reason. Furthermore, it is our capacity for
reason to allow us to link these moral considerations to action. That is, not only can
we figure out what the moral law demands, we can exercise our agentive capacities
in order to act accordingly. This is what it means to be an autonomous moral agent.

But rationality for Kant isn’t merely about legislating and acting according to the
moral law. The wick of rationality holds alight within us the flame of dignity. It is in
virtue of our rational capacity that we enter the moral realm not merely as agents,
but as moral subjects with inherent moral value. Our participation in the moral realm
entails that we personally constitute absolute limits upon the possible actions of
others. Kant’s political liberalism famously dictates that people ought to be as free as
possible, where that freedom does not infringe upon the equal freedom of another
(Kant 1991/1797, 187-8). Interpersonally, people are limited by the absolute limits of the
dignity of oneself and others. We can never act in a way that fails to respect the
dignity of ourselves and, perhaps more importantly, that of another.

C. Universal Dignity

\textbf{From Kant to Universal Dignity}

There is significant distance between Kant’s development of his moral system and
the advent of modern clinical ethics. Over time, the notion of dignity that has evolved
in clinical ethics has moved away from the strictures of Kant’s philosophical
perspective, and moved toward a more general understanding of the nature of
dignity. I refer to this as \textit{the universal account of dignity}, or simply \textit{universal dignity}.
To facilitate this move, it is helpful to understand some of the connections between
Kantian dignity and universal dignity. First, I discuss these connections and the
broader influence of Kantian ethics. Second, I provide a brief overview of the

\(^9\) This is a clear-cut and traditional interpretation of Kant’s perspective on a case like this. For a
more nuanced discussion, see Thomas E. Hill Jr.’s “Making Exceptions Without Abandoning
the Principle: or How a Kantian Might Think about Terrorism” (1992).
development of universal dignity in Western clinical ethics, in particular during and
after the Second World War. Finally, we'll look at some of the problems that follow
from this conception of dignity, in particular within the context of clinical ethics.

Universal dignity is responsive to the idea that for most of us, philosophers or
not, dignity conveys two connected ideas. The first is that of fundamental moral
value. That is, dignity conveys the characteristic, whatever it may be, in virtue of
which we have moral standing. The second is the limits this kind of status entails on
the actions of others. That is, if we have moral standing, this means that others and
potentially ourselves are limited in the kinds of conduct that is morally permissible.
Combined, these ideas simply convey that (1) we have moral status and (2) this
means that we cannot be arbitrarily killed, tortured, exploited, and so forth. On this
universal account of dignity, dignity is the feature of humans that gives us moral
status. It imposes strong, if not absolute, limits on potential actions. It can be
violated, but not reduced. That is, the moral value of human beings is itself
unassailable, but it can be infracted upon. This view of dignity remains broadly
Kantian, but it is generally used without explicit reference to Kant's broader (moral)
work, and measured against other potentially authoritative concepts, rather than
alternative interpretations of Kant.

Kant's theory of ethics is so influential that the entire family of views—also
known as deontology, non-consequentialist or non-teleological ethics, and duty
ethics—is often simply referred to as Kantian ethics (Beauchamp and Childress 2006,
343). It is undeniably among the most influential ethical theories in the Western
tradition, and if Kant's direct influence is vast, certainly his indirect influence is
immeasurable. While it's difficult to quantify this kind of influence, we can get a
sense of the influence of particular works by looking at how widely they are cited.
Google Scholar provides limited metrics on citations (data as of February 2022),
indicating that the DeGruyter edition of Kant's The Metaphysics of Morals has been
cited over 13,000 times. Kant's political philosophy is a primary influence on Rawls'
theory of justice, and the original edition of John Rawls' A Theory of Justice by
comparison has been cited just over 100,000 times. Kantian ethics is ubiquitous in
clinical ethics as well. In clinical ethics, the Kantian view of dignity and ethics is
related to the popular principles approach, the seminal text for which is Tom
Beauchamp and James Childress' Principles of Biomedical Ethics. Google Scholar
indicates that the fifth edition of this work has been cited nearly 33,000 times.¹⁰

The principles approach has its roots in the Western formalization of bioethical
standards of conduct. One defining moment in this development was the laying

¹⁰ The approach itself also locates its source in the tradition of Russian intuitionism.
Intuitionism, while metaethically ambiguous, offers a set of principles from which to engage
in moral deliberation. While it is less stringent than duty-based approaches, it doesn't rank its
principles, which makes it difficult to navigate conflicts in values. This problem also exists for
the principle approach, which it inherited from its intuitionists and Kantian antecessors.
bare of atrocities in the Nuremberg Trials. Indeed, part of the horror of WWII was the vast dehumanization of people. On the part of the Nazis one of the ways this occurred was through human medical torture, primarily on people with disabilities, POWs, Romani, and Jewish people (Micozzi 1993, n.p.; Müller-Hill 1998, 10-22; Faden and Beauchamp 1986, 153). These war crimes led to the development of the Nuremberg Code of Research Ethics (Faden and Beauchamp 1986, 153).

Unfortunately, citizens of the world would soon learn that the human medical torture did not cease after the defeat of the Nazis. The Tuskegee Syphilis Study, which ran in the United States for forty years, from 1932 to 1972, only ended due to an information leak. It constituted an enormous injustice against Black Americans, compounded by a context of centuries of oppression (Centers for Disease Control and Prevention 2021, n.p.; Newkirk II 2016, n.p.). The study had 600 test subjects, and by the end of the study “28 of the men had died of syphilis, 100 died from complications related to syphilis, 40 of the patient’s wives were infected with syphilis, and 19 children were born with congenital syphilis” (Magner and Kim 2018, 138). The effects of this study continue to reach far beyond these initial statistics. After centuries of subjugation and maltreatment, the Tuskegee revelations further eroded trust in the medical system among Black men. A groundbreaking study by Marcela Alsan and Marianne Wanamking, published in their “Tuskegee and the Health of Black Men,” estimates that the “decrease in the life expectancy of black men attributable to the Tuskegee revelation represents approximately 35% of the racial gap in male life expectancy in 1980” (Alsan and Wanamaker 2018, 449-50). That is, the Tuskegee study and the distrust it reinforced alone are responsible for an eighteen month reduction in life expectancy among American Black men (Alsan and Wanamaker 2018, 449-50). The Tuskegee study violated the Nuremberg Code, which was produced during the course of the experiment, and was a major contributing factor to the development of the Ethical Principles and Guidelines for the Protection of Human Subjects of Research by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Newkirk II 2016, n.p., Sim 2010, 173). This document is better known as the Belmont Report, which continues to be a keystone text in the bioethics literature, and codified the principles of “respect for persons, beneficence, and justice” in research with human subjects (Fischer IV 2016, n.p.; National Commission 1979, n.p.; Sim 2010, 173).

These major developments in bioethics—themselves the result of the force of global historic events—coincided with a resurgence of Aristotelianism in ethics, initiated primarily through the work of G.E.M. Anscombe and Philipa Foot (Driver 2018, n.p., Hacker-Wright 2021, n.p.). Anscombe in particular argues for the need for

---

For Foot, see for instance her monograph Natural Goodness (2001), or the collections Moral Dilemmas and Other Topics in Moral Philosophy (2002) and Virtues and Vices and Other Essays in Moral Philosophy (2002) (cited in Hacker-Wright 2021, n.p.). For Anscombe, see in
alternatives to deontological and utilitarianism moral theories in the aftermath of World War II (Anscombe 1981 (Orig. Pub. 1957), 70-1; Anscombe 1958, 2-3). It seems that our extant systems and institutions—the ones that were able to give rise to these moral catastrophes—were demonstrably not up to the task of avoiding them. Given the ubiquity of utilitarian ethics and deontological ethics, virtue ethics offered an appealing alternative. Aristotle’s account of humanity is often considered more inclusive than that of its competitors. He takes into account a broader set of capacities when he attempts to define human nature. Nevertheless, it prioritizes the human capacity for reason, and aims exclusively at the realization of basic human constitutive ends of wisdom and character. If we think about dignity as a dish made up of various ingredients, then we may conclude that while dignity is not on Aristotle’s menu, we can see that a lot of the ingredients are present. Yet, as Anscombe remarked about the notions of moral goodness and obligation in Aristotle, one cannot from our contemporary perspective discuss these without feeling like one’s “teeth don’t come together in a proper bite” (Anscombe 1958, 2). The same holds true for dignity. The closest we can get to a substantive notion of dignity in Aristotle is the state of living a good life, which doesn’t map on particularly well to our pre-theoretical notion of dignity.

Major developments in bioethics and revitalized interest in virtue ethics can both be traced back to the post-WWII reconstruction period and the desire to create systems and institutions that were accountable to the people and able to avoid mass suffering and death. The development of moral character in particular must have looked incredibly attractive, for it is difficult to imagine a magnanimous person playing any part in the Soah, giving permission to drop the atomic bombs on the civilian centers of Hiroshima and Nagasaki, or approve a deadly study into a dangerous bacterial infection without the intention of treatment or concern for (informed) consent. In the United States in particular, the practice of medicine was largely free of any substantive notion of consent until the mid-twentieth century. In fact, the history of how informed consent became one of the keystones of ethical conduct in western medicine can be traced through a series of influential court cases. Among these, Schloendorff v. New York Hospital (1914) established the


12 Aristotle also uses dignity in the heterogeneous sense of status: “For the truly good and wise person, we believe, bears all the fortunes of life with dignity” (Aristotle 2004/c. 330 BCE, 18). So dignity is a quality of the good person, but dignity is not definitive of their personhood. Moreover, “dignity” here is but one of several possible translations of the term εὐχερήμων, which H. Rackham translates in the Perseus Collection as “seemly,” and which the Perseus dictionary defines as “elegant in figure, mien and bearing, graceful” (Rackham n.d./1934, 1101a.1; Bywater n.d./1894, 1101a.1; “εὐχερήμων” n.p.). This is what Schroeder calls aristocratic dignity, which I group under the broader category of status dignity. This notion of dignity is not particularly relevant to Aristotle’s ethics.
requirement for consent in the United States after Mary Schloendorff filed suit when her physician performed surgery against her explicitly stated wishes. The surgery resulted in gangrene which led to the amputation of her arm. The court ruled that Schloendorff was the victim of medical battery (Faden and Beauchamp 1986, 123).\footnote{See also ("Consent and Informed Consent: Basic right to consent to medical care - Schloendorff v. Society of New York Hosp., 105 N.E. 92, 93 (N.Y. 1914)").}

The requirement for informed consent was not established in the United States until 1957, when \textit{Salgo v. Leland Stanford Jr. University Board of Trustees} set standards that exceeded those of medical battery. This happened in response to the suit filed by Martin Salgo, who was paralyzed as the result of an aortography, whereas he was never informed of this risk (Green and MacKenzie 2007, n.p.; Faden and Beauchamp 1986, 125).\footnote{See also ("Salgo v. Leland Stanford etc. Bd. Trustees").} The notion of informed consent was subsequently clarified by \textit{Natanson v. Kline} (1960) and \textit{Canterbury v. Spence} (1972), the latter of which in particular constituted a move away from paternalism in medicine, insofar as it established a standard whereby “practitioners [were now required] to disclose the risks that a reasonable patient would want to know” (Green and MacKenzie 2007, n.p., italics added).\footnote{See also (Faden and Beauchamp 1986, 129, 132-8).}

Informed consent is an invaluable ethical standard, but it is not itself foundational. Informed consent only makes sense when we understand human beings as being able and free to affect their own lives. This is usually explained in terms of the ability to reason and act according to reason. This capacity for autonomy or agency is often taken to entail the ethical notion of respect. In other words, when we respect someone, we treat them as a being that has the capacity to affect their own life. There is a cluster of concepts here: respect, autonomy, humiliation, and paternalism. At times, it seems like these concepts are inextricably related, in a way that makes it impossible to define one without making reference to others. Precisely how we define each term affects how we understand the nature of ethics and standards for (surrogate) decision-making. Traditional theories of ethics and dignity have often had exceedingly high requirements for autonomy and agency. Combined with a frequent conflation of moral agency and moral patience, the result has been an excess of paternalism, especially in cases of surrogate decision-making. This problem has largely persisted in more modern iterations of their respective perspectives.

Dignity is often invoked in the context of medicine and clinical ethics, not merely in the abstract and in the literature, but by patients, loved-ones, physicians and other medical staff, as well as major medical organizations and institutions. These all rely on the concept of dignity to do profound work in making claims about appropriate treatment. For instance, the following statements by major medical organizations all reference dignity in some of their primary policies or statements (bolded emphases added):

AS A MEMBER OF THE MEDICAL PROFESSION ... I WILL RESPECT the autonomy and dignity of my patient; [and] ... I WILL PRACTISE my profession with conscience and dignity and in accordance with good medical practice.

Centers for Disease Control and Prevention’s “Pledge to the American People” (2018):

Treat all persons with dignity, honesty, and respect.

American Medical Association’s “Principles of Medical Ethics” (2001):

A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.

Cleveland Clinic's “Lesbian, Gay, Bisexual and Transgender Health Care” (N.d.):

While all Cleveland Clinic providers are committed to creating a safe environment that maintains the respect and dignity of all patients, some providers have specific interests in working with the LGBT community.

I maintain that, here and elsewhere, dignity is invoked for good reason! The term has great moral weight, and its use points to the fact that we’re talking about something that matters greatly. This is clear from the examples above, where health care providers are aiming to publicly affirm and solidify their commitment to their patients.

Beyond the expression of this commitment, the way we conceptualize dignity helps give meaning to a set of related terms that are central to applied ethics. Largely in accordance with the Kantian account, universal dignity entails that to respect a person means responding appropriately to another’s dignity, and always treating a person as an end and never merely as a means. Autonomy refers to our freedom to choose and act, and (for Kant) to do so in accordance with what is morally required. Finally, in the context of universal dignity, paternalism entails overriding the autonomy of an individual in order to protect their dignity for their sake. These concepts, and how we understand them, are closely connected to the meaning we give to the term dignity. It is therefore important to be aware that changes to the latter may have consequences to the former as well.
D. The Problems with Universal Dignity

There are several difficulties that are standardly raised about Kant’s view. For our purposes, the most pressing concern is the problem of conceiving of reason as the ground of morality, because this creates difficulty for those in a medical context whose capacity for reason is limited. This section looks, first, at the problem of irresolvable conflicts. Next, it looks at the issue of paternalism, and how this shows up in the case of end-of-life decision-making, and surrogate decision-making for unrepresented patients and patients with disabilities. Given the vast literature on Kant, neither the foregoing overview of his theory, nor the ensuing criticisms are exhaustive. Much ink has been spent in support and opposition to competing interpretations of Kant’s view, its entailments, and applications. For now, the aim is to raise some problems that any account of dignity, though in particular Kantian ones, must address.

The Problem of Irresolvable Conflicts

In the previous section we looked at the ways in which dignity is central in healthcare policy, mission statements, and clinical ethics. In fact, the practice of health care itself seems to be predicated on accepting the moral status of human beings, and advancing people’s interest in health. Recall that universal dignity entails that (1) we have moral status and (2) this means that we cannot be arbitrarily killed, tortured, exploited, and so forth. Insofar as dignity constitutes fundamental moral status (#1), the concept is important but generally accepted. And insofar as universal dignity acts as a limiter on actions (#2), it is often too general to be meaningful in a clinical context. That is, while universal dignity may allow us to argue against torture and bombing civilian populations, it’s not well suited to the kind of fine-grained, highly variable cases we encounter in a healthcare context.

---

16 This includes Mill’s famous rebuttal that Kant merely shows that “the consequences of their universal adoption [of the most outrageously immoral rules of conduct] would be such as no one would choose to incur” (Mill 2001, 4). Kant would, of course, deny this change. He explains that “nothing other than the representation of the law in itself, which can of course occur only in a rational being, insofar as it and not the hoped-for effect is the determining ground of the will, can constitute the preeminent good we call moral” (Kant 2006, 14). Yet, though Mill’s charge isn’t a knockdown argument against Kant’s view, it does seem that Kant gives a lot of weight to the desirability of a world in which a maxim of action is universal. This, of course, is not to say that Kant is secretly a utilitarian, and this isn’t Mill’s suggestion either. Rather, Mill attempts to demonstrate the universal concern for consequences that is centralized in his own view. The fact that Kant’s concern is with the plausible outcome of a hypothetical universal, rather than the actual or reasonably acceptable outcome of individual actions or policies, is of little consequence to the sting of the objection.
This difficulty in navigating conflict becomes clear in practice. For instance, in the introduction we saw how the divergence in discussion on active euthanasia and physician assisted suicide in Canada, in spite of the fact that both the opposition and those in support of the MAID legislation attempt to ground their position in some notion of dignity. It seems that we can make sense of both the claim that prolonged suffering against the person will violate their dignity and autonomy, as well as the claim that the active termination of life violates a person’s dignity because it seeks to destroy their inherent value. The American Medical Association (AMA) also recognizes this conflict. As a result, their Code of Medial Ethics Opinion offers competing opinions on Physician-Assisted Suicide, citing that “Supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity; they diverge in drawing different moral conclusions from those underlying values in equally good faith” (American Medical Association 2017, n.p.). The next section looks more closely at this AMA Opinion, but suffice it to say for now that reference to universal dignity alone is insufficient in drawing conclusions on end-of-life decision-making.

Dignity is an incredibly powerful force in metaethics. It has the ability to infuse its object with moral meaning, and on the universal account it imposes hard limits on potential courses of action. As we have seen, this commendably entails the moral impermissibility of murder, torture, and bombing civilian populations. It also enshrines the moral status of truth, upholding promises, and general beneficence as fundamentally good. However, Kant’s moral view does not admit of true moral dilemmas, where there is no right course of action, or where every course of action is morally compromised (Timmerman 2013, 36, 51). This rejection of dilemmas has, in a way, been inherited by the universal account of dignity. As a result, this framework frequently imposes strict limits on potential courses of action, in particular in the context of end-of-life decision-making. And when pushed away from the strictures of Kant’s philosophical outlook, universal dignity offers a framework that entails conflicting analyses of cases, resulting in radically different recommendations for action.

The Problem of Paternalism

While we often think about medicine in terms of duties the physician has, and there is a robust tradition in clinical ethics that uses duty ethics as its foundation, the classical critique against Kantian ethics concerning its rigidity is one it also faces in the context of clinical ethics. Moreover, accepting Kantian ethics as the foundation of bioethics entails a focus on the duties physicians have, which has two important consequences. First, it minimizes the moral features of the physician-patient relationship as it attempts to work these out in terms of patient-related duties rather than relational features. This has among its potential consequences that patient
autonomy becomes secondary to physician duties toward patients. This brings us to the second entailment, namely that Kantian ethics tends toward excess paternalism. Since our duties to the patient are primary, this leaves less room for the patient’s self-determination. Even if we take respect for patient autonomy to be a primary value, this can easily become entangled in a web of conflicting duties: preserving life, preserving limbs, obligations to civic law, etc. This difficulty may be illustrated through the following case.

Case—Capacity for Preferences

[The patient is a] Forty-one-year old male who at age twenty-five had been involved in a car accident that left him paralyzed from the waist down and with a traumatic brain injury … He had a court-appointed guardian and had lived in group homes since becoming paralyzed … He was admitted to the hospital for stage 4 decubitus ulcers on his legs resulting from lack of hygiene and refusal of wound care … the patient consistently refused wound care … [and] denied that he was paralyzed. [Treating physicians were considering three potential courses of action, namely] “a six-week course of intravenous antibiotics [requiring] six weeks of prolonged restraint, amputation below the knee, or no curative action but comfort care in the hospital and then hospice once he became septic. (quoted from Wasserman and Navin 2018, 33, 32)

How do we analyze this in terms of duties? First, patient autonomy. The patient has a stable preference against amputation, but since the patient lacks capacity this is not, in Kantian terms, an autonomous decision that they can make independently. This is, after all, why we’re contemplating the case in the first place. The physician also has a professional and moral duty to preserve a patient’s life and limbs if there is a realistic chance of success. In this case, it seems that since the patient’s capacity for decision-making is undermined, the physician’s duty to save life and limb takes priority. This means that we have to set aside the patient’s expressed wishes in favor of the physician’s duties. The clear overwriting of a patient’s preferences should give us pause, even if they are ultimately incapacitated for a particular decision. What cases like this demonstrate is that duty-based thinking can be challenging in the context of applied ethics, where the variables are infinite. Moreover, the centrality of rationality that is common in these approaches is not well suited for clinical ethics, where capacity is often an issue.

One popular alternative to Kantian ethics is the principles approach, which articulates certain principles of bioethics that guide moral decision-making in medicine. One such approach is that articulated by Beauchamp and Childress in their seminal The Principles of Biomedical Ethics, which codified the principles of autonomy, nonmaleficence, beneficence, and justice (Beauchamp and Childress
2006/1979, 99, 149, 197, 240). Here, autonomy requires that the patient make a
decision, nonmaleficence requires that the physician does not cause harm,
beneficence requires that the physician acts to the benefit of the patient, and justice
requires an appropriate distribution of resources. Which of these values ought to
ultimately decide the outcome of the case is not clear, because the principles are put
on equal footing. The principled approach may therefore help illuminate the case,
but it does not independently resolve it. What these views have in common is that
they focus on the moral responsibilities of the physician. As a result, the patient is
pushed aside. Their autonomy and preferences matter, but only insofar as they figure
into the physician’s moral obligations. These views prioritizes the physician, and
demands that they figure out what is required of them and act accordingly. This
action is, subsequently, imposed upon the patient. This problem arises out of the way
in which the universal account understands dignity and autonomy to be tied to our
rational capacities, which is a clear carry-over from its Kantian roots. This entails that
when someone does not have the capacity for decision-making, their reduced
rational capacity threatens to undermine their autonomy and by extension their
dignity. In order to protect their dignity, their autonomy must be transferred, as it
were, to a third-party that can realize autonomous decision-making in their stead.
However, this is ultimately counterproductive. Due to the generally presupposed
metaphysical ties between dignity and autonomy, it is difficult to conceive of having
one without the other. To promote paternalism to save a person’s dignity is to pay off
a loan with a credit card. Ultimately, we must either understand the patient as
having dignity, which is violated by paternalistic interference, or the patient, lacking
autonomy, does not have dignity, in which case there are no direct moral standards
for decision-making. If we are to avoid moral skepticism, then we must reject the
latter, and so we are forced to accept that the transfer of decision-making power
frequently involves morally suspect paternalism. Therefore, ethical surrogate
decision-making requires an account of dignity that disentangles it from the
traditional conception of autonomy.

Universal Dignity and the Problem of Medical Assistance in Dying

Kant explains in his considerations of suicide that the categorical requirement that
we treat “humanity as an end in itself” applies to our own humanity as much as it
does to that of others, and to kill ourselves in order to make our plight tolerable
would be to make “use of a person merely as a means to maintain a tolerable
condition up to the end of life” (Kant 2006, 38, original italics). Since for Kant
autonomy is our freedom to act in accordance with the moral law, and the moral law
generally precludes the hastening of death, it seems that Kant puts significant limits
on end-of-life decisions. Let’s consider a similar case to the one Kant considered, but
place it firmly in a medical context, i.e. a case of physician assisted suicide. This case
Case—*(How) Do We Choose Our End?*

The patient is a 46 year old female patient. She came in “feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. They did a bone-marrow biopsy and she was diagnosed with acute myelomonocytic leukemia. The oncologist proposed a course of induction chemotherapy, followed by consolidation chemotherapy, and finally a bone-marrow transplant. The survival rate of this course of treatment is about 25%. The survival rate of no treatment is about 0%. The oncologist met with the patient to inform her of the diagnosis and had made plans to begin induction chemotherapy that afternoon. This enraged the patient, who refused treatment. When the patient saw their treating physician several days later, they remained steadfast in their refusal for treatment, with limited support from their family. A couple of weeks later, the patient came to the physician requesting barbiturates to aid in sleep. While barbiturates can be a powerful sleep aid, their non-prescription use can also result in death. In conversation with the patient it becomes clear that they are planning to use it as a sleep aid, but that they are also aware of its secondary use, and wish to have enough of the medication to be able to commit suicide. By law, the physician is banned from providing assistance in patient suicide. The physician must choose whether or not to assist the patient. *(Originally from Quill 1991a)*

What might a clinical ethicist say about this case, especially in terms of universal dignity? First, it seems that the patient is trying to control the conditions of their death in a way that coheres with the death with dignity framework for end-of-life decisions. We can understand dignity here in at least two ways. One is to understand the dignified conditions of death to be the ones that avoid lack of independence and privacy that often mark the medicalized end of life. The other is to understand dignity as being able to exercise one’s autonomy at the end of life by controlling the when-and-where of one’s death. Neither interpretation of dignity at play here is that of inherent moral value, i.e. universal dignity.

If we were to evaluate the case from a strictly Kantian understanding of dignity, then it seems that we must conclude that the physician ought not to assist the patient in bringing about death. Indeed, given Kant’s articulated position against suicide, this appears to be a prime example of a case where death, and therefore the destruction of human life, would be a mere means toward the end of alleviating suffering. There is more to say if we move to evaluate the case from the more contemporary, universal account of dignity. Here, it is worthwhile to look more
closely at the American Medical Association Code of Ethics with respect to the question of physician assisted dying (PAD).

In the mid-1970s, James Rachels discusses the AMA position on euthanasia in his “Active and Passive Euthanasia” (2007/1975). He cites the “statement adopted by the House of Delegates of the American Medical Association on December 4, 1973,” which states that “The intentional termination of the life of one human being by another—mercy killing—is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association” (Rachels 2007, 64, citing American Medical Association 1974, n.p.). In evaluating the AMA position on PAD, it is helpful to follow Rachels titular distinction. Here, passive euthanasia refers to the lack of provision or removal of life sustaining medication, technology, and processes. This may include turning off a ventilator, enacting a do not resuscitate order, stopping chemotherapy treatments, and so forth, and is often accompanied by a move to comfort care. By contrast, active euthanasia refers to the direct provision of the means to the end of life. This is generally achieved through the injection of a lethal substance. Notably, the AMA’s expression of discontent with mercy killing in this statement seems to extend to physician assisted suicide (PAS) as well. PAS is any kind of aid a physician provides in a patient’s suicide, including information or medication.

The AMA has since revised their codes of ethics, but the key provisions regarding physician assisted dying remain virtually unchanged. The current Code of Medical Ethics Opinion 5.7 Physician-Assisted Suicide states that physicians “Must respect patient autonomy” (American Medical Association 2017, n.p.). However, it also states that “Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks,” and that “Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life” (American Medical Association 2017, n.p.).

It should be noted that the AMA provides two distinct provisions with respect to these kinds of end-of-life decisions, namely the one above that supports an outlook that is generally opposed to active euthanasia, and one that supposedly supports active medical assistance in dying. The two policies are prefaced by a note addressing the contentious nature of the debate concerning PAD. It notes that Thoughtful, morally admirable individuals hold diverging, yet equally deeply held, and well-considered perspectives about physician-assisted suicide. … Guidance in the AMA Code of Medical Ethics encompasses the irreducible moral tension at stake for physicians with respect to participating in assisted suicide. … Opinion 1.1.7 articulates the thoughtful moral basis for those who support assisted suicide” (American Medical Association 2017, n.p.). However, as Eliza Blanchard and Lynn Stoller note in “Action Steps and Solutions for Physicians’ Exercise of Conscience,” the Opinion that is meant to support PAD, is more accurately characterized as an expression of the
appropriate conditions for the conscientious refusal of physicians (Blanchard and Stoller, 2016, 243, 246-7). It seems to provide guidance for physicians who operate in regions where PAS is legal, but who have reasons not to provide active assistance in dying. This means that the medical profession, insofar as the AMA is representative thereof, largely maintains the outlook it formalized in the 1970s against active euthanasia. This ultimately supports the preservation of the fundamental human value of dignity over other considerations. It is clear, then, that in balancing the competing concerns of dignity, autonomy, and the principle of nonmaleficence, the profession in general seems to conclude against physician assisted suicide and active euthanasia. Dignity, as the inherent moral value of human beings, outweighs both dignity as freedom from humiliation and autonomy.

It’s notable that Rachels, in my view convincingly, argues that the AMA policy regarding euthanasia is incoherent, not from an analysis of dignity or autonomy, but from a moral analysis of the concern with avoidance of harm and suffering. In short, he argues that the very same (consequential) reasons we have for permitting passive euthanasia also support active euthanasia. This approach is influenced at least in part by the fact that Rachels is arguing from a broadly utilitarian perspective. He never mentions the concepts of dignity or autonomy in the essay, and I cannot help but think that this is because the concepts are very slippery. Certainly the factors that Rachels makes reference to in arguing for the moral equivalence between active and passive euthanasia can be expressed in terms of dignity and autonomy, but this would merely bring it to even odds with the AMA statement, which can be expressed in similar terms.

This problem can also be expressed as a conflict in the principles of medical ethics, where dignity/autonomy and nonmaleficence pull in opposite directions, and where the principles themselves offer no conclusive means of navigating this conflict. Beauchamp and Childress are clear, for instance, that “We do not hold ... that the principle of respect for autonomy overrides all other moral considerations” (Beauchamp and Childress 2006, 99). The universal account of dignity as well as the AMA Code of Ethics seem to resolve this by generally disallowing physician assisted suicide and active euthanasia. The death with dignity movement and Rachels resolve this in favor of the moral permissibility of physician assisted suicide and active euthanasia. Even in the latter case, however, conflict persists, since this notion of dignity also complicates the legislative discussions concerning PAD. This has been made evident by the recent discussion, noted in the introduction, concerning death with dignity laws in Canada (Parliament of Canada 2001, n.p.). Here, people with disabilities oppose medical assistance in dying legislation at least in parts on the grounds that it threatened to undermine their dignity (Dying With Dignity Canada n.d., n.p.). As Meagan Gillmore reports in “‘Catastrophic Pandora’s box’: Disabled Ontarians speak out against proposed MAID law,” disabled Canadians are concerned with the implications of the bill. They argue that in the context of a system that fails
to adequately address the needs of disabled people, the expansion of MAID legislation is coercive (Gillmore 2021, n.p.). It pressures those who struggle with accessible healthcare, housing, work, and other social and personal needs to choose death over these social hardships. As such, “People with disabilities, including in particular those who are marginalized, Black, Indigenous, racialized and poor, have warned that Bill C-7 will undermine their dignity and put their very lives at risk” (quoted in Gillmore 2021, n.p.).

**Reason, Dignity, and Disability**

For Kant, our dignity, our priceless moral worth, is based on our membership in the kingdom of ends. When our rational capacities are destroyed by illness, this has the potential to undermine our dignity and autonomy, which puts us at ever greater risk for paternalism. While Kant does not directly address the issue of surrogate decision-making, he does state that “the ends of a subject who is an end in itself must as far as possible be also my ends” (Kant 2006, 39). The “as far as possible” here is limited not merely by practical considerations, but also by moral ones. Human dignity, the status of being an end in itself, is “the supreme limiting condition of the freedom of action of every human being” (Kant 2006, 39). This means that in all things, including surrogate decision-making, while the individual along with their preferences and desires matter, we are still subject to and constrained by the universal laws of morality.

Furthermore, in the case of surrogate decision-making, we can see a potential conflict between Kant’s formulations of the categorical imperative. Where the universal principle entails that we must decide the same course of action for people in similar situations, the kingdom of ends formulation complicates this. Seeing each individual as a unique human agent might entail that different courses of action are appropriate, even contrary ones in highly similar scenarios. The only way to square these with Kant’s decision-making procedure is to formulate maxims so specific that universalization becomes a set of one. So there is a significant tension between universality and autonomy—one we ought to balance ourselves when we make decisions for ourselves, but one that is potentially much more difficult when deciding for another. Universal dignity requires that we respect others as autonomous

---

17 Relatedly, we can generally formulate a maxim that corresponds to an action in multiple ways, focusing on different aspects of the situation or our motivation, at various levels of specificity or abstraction. How we formulate this maxim may affect whether or not it is universalizable. Kant famously considers the ethics of lying, asking “would I indeed be content that my maxim (to get myself out of difficulties by a false promise) should hold as a universal law (for myself as well as for others)? and could I indeed say to myself that every one may make a false promise when he finds himself in a difficulty he can get out of in no other way?” (Kant 2006, 15). He quickly concludes that under such a universal scheme, “there would properly be no promises at all, since it would be futile to avow my will with regard to my
rational agents. However, in cases of surrogate decision-making, it is precisely these agentive capacities that are undermined. Insofar as we understand Kantian autonomy to be about basic, even latent rational capacities, this does not change the difficulty in reconciling these requirements in cases where extant rational capacities are very different.

How to best bring people who fall short of Kant's vision of the rational agent into our kingdom of ends is still an active area of conversation, especially in the philosophy of disability literature. For instance, John Vorhaus, in his “Respect, Identification, and Profound Cognitive Impairment” (2020), argues that “people with profound and multiple learning difficulties and disabilities” count on Kant’s account based on his extension of dignity and respect to infants and young children (Vorhaus 2020, 399, 411). Vorhaus suggests that people with disabilities which prevent them from having a perspective on the world may be included based on their species membership or “duties owed to all persons” (Vorhaus 2020, 411). But even Vorhaus admits that “It is by no means certain that the approaches mentioned here can succeed in conferring on all human beings without exception a moral status that demands respect” (Vorhaus 2020, 411).

In contrast to Vorhaus’ inclusive view, Samuel J. Kerstein, in “Procreation and Intellectual Disability: A Kantian Approach” (2020), suggests a narrower

---

future actions to others who would not believe this avowal ... and thus my maxim, as soon as it were made a universal law, would have to destroy itself” (Kant 2006, 15). Indeed, Kant stands (in)famously firm on the issue of lying, going so far as to argue that one should disclose the presence of refugees in one’s house if someone intent on murdering them comes to your door (Kant 2012/1889, n.p.). In his “Autonomy and Benevolent Lies” (1984), Hill argues for a strong presumption against benevolent lies, not from Kant's oft rebuked universalization-argument, but from autonomy. He maintains that “respecting a person’s capacity for distinctly human values implies that, other things equal, it is worse to presume that someone prefers comfort to some other declared value than to presume the opposite” (Hill 1984, 63). He later notes that “Even if benevolent lies do not violate a right, they still deprive people of a realistic picture of their situation. Insofar as having such a realistic picture is needed for genuine rational control over one’s life, to that extent the benevolent liar fails to promote an ideal end” (Hill 1984, 263-4). So whereas cases in which lying may be permissible exist, they are rare, and rely on an explicit request of having the truth withheld, without any indication that this desire has changed (Hill 1984, 263). Nevertheless, it seems we can come up with a case wherein lying would be permissible, and perhaps even morally required.

Consider Mr. Chen, who is living in a long-term care facility with advanced Alzheimer’s. Years earlier, they had a cat named Tiger, who had since passed away. Mr. Chen would often ask the staff about the whereabouts of their cat. When the staff told Mr. Chen the cat was dead, he would become profoundly sad. Not long after, Mr. Chen would inquire again. Beforelong, the staff would change their story, informing Mr. Chen that Tiger had run down the hall for some canned tuna, but would be back soon. In this case, it seems that to continually insist on causing Mr. Chen grief is unnecessarily cruel. A simple, inconsequential lie saves him from repeat avoidable suffering. While this is not a knock-down argument against Kant’s injunction against lying, the lie in this case does seem morally permissible and otherwise harmless, and does not interfere with autonomy, as is Hill's concern.

---

18 Vorhous cites (Kant 2001b, 670-1; Kant 2007, 127-8, 268-9, 328-30).
understanding of membership in the kingdom of ends. Kerstein offers a “reconstruction ... of part of the Formula of Humanity,” which sets limits on our actions that affect other persons (Kerstein 2020, 745). He argues that “A being is a person only if it has the capacities to: set and pursue ends; strive for coherence among its ends; be self-aware; conform its actions to practical rules that specify means to ends; and be motivated to act by some moral imperative” (Kerstein 2020, 746). This obviously limits the notion of personhood and therefore the extent to which dignity applies to those who have certain cognitive disabilities, as well infants, embryos, and future persons. Kerstein argues that if the personhood threshold is not met, then there is no violation of dignity in being treated merely as a means (Kerstein 2020, 476).

While the literature shows that people who are neurodiverse, neurologically impaired, or incapacitated are not necessarily excluded from the Kantian moral realm, the fact that their fit is somewhat uneasy points to a problem that appears to be inherent in any moral account that is committed to the primacy of reason. The close ties between reason, dignity, and autonomy mean that any kind of impairment risks paternalism. This is a significant, arguably unacceptable cost in an area that is meant to be accountable to people in just such a situation, i.e. healthcare.

**Moving Forward**

The universal account of dignity is not ideally suited to addressing clinical ethics cases. There may be a deeper question here, as to why this is the case, and how we can go about addressing this problem. First, we could attribute this practical difficulty to our abstraction away from pure Kantian ethics. We could address this by moving back to a full-fledged Kantian ethic, where dignity expresses our status of a rational and autonomous agent, and where this status constitutes an uncompromising part of the normative framework. However, this is unrealistic, first because traditional Kantianism is not a common tool in clinical ethics. And second, because some of the main issues with universal dignity broadly construed are inherent from the traditional Kantian framework. A return to full-fledged Kantianism will therefore entail similar problems in navigating moral conflicts as does the more general universalist conception of dignity.

Second, it could be that the Kantian understanding of dignity alone is insufficient in providing moral guidance. In this case, we can attempt to resolve the conflict by supplementing with other concepts. As we have seen, broadly Kantian approaches to clinical ethics often employ a range of concepts including autonomy, beneficence, respect, and justice (Fischer IV 1986; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979; Beauchamp and Childress 1979/2009). Unfortunately, these concepts are either closely connected to the Kantian conception of dignity, or they have abstracted into
a more general iteration of their traditional source. In the former case, they are conceptually tied to reason in a similar way as dignity, and will reproduce the problems that come out of this connection. In the latter case they suffer from the kind of indeterminacy we are attempting to address, and we can therefore expect that they are similarly ineffectual in navigating particular moral conflicts.

Third, we can get rid of the notion of dignity. We have already seen that there are theorists that have argued for this kind of dignity skepticism, either because they find the concept of dignity pernicious, or because they find it too ambiguous. However, as I argued above, I think that given its prevalence in ethical, philosophical, and political discourse, dignity is doing sufficiently important work such that the concept shouldn't be written off except as a last resort.

Finally, we can provide an alternative account of dignity. This may sound *ad hoc* and arbitrary, but since the discourse concerning dignity is highly variable, there are grounds for considering other interpretations for dignity. Given this variability, such an alternative account may be broadly revisionist, while still being able to tap into important intuitions and extant usages of the term. The problem we face, then, is that we seem to rely on the concept of dignity to do important moral work in health care, but the universal account of dignity is not ideally suited to the job. To see that universal dignity, as a key ethical concept, can fail to straightforwardly apply in cases where patients are arguably at their most vulnerable speaks to its insufficiency. This emphasizes the importance of rethinking either the role of dignity bioethics or its conceptualization.
What can remedy the problem identified in the previous chapter, namely the fact that we seem to rely on the concept of dignity to do important moral work in health care, but the universal account of dignity is not ideally suited to the job? We need a view that lifts the patient out of the fray of moral considerations. They are not merely a part of the moral puzzle: they are active interlocutors in the moral dialectic. This demands a social understanding of dignity. In light of this, I argue for a relational conception of dignity that is grounded in a person’s narrative. I develop this understanding of dignity in contrast to universal dignity, and against the background of discussion of other relational views of dignity, in particular those offered by David Luban (2005), Suzy Killmister (2010, 2016, 2017, 2020a), and Linda Barclay (2016, 2018, 2020). In this chapter, I offer a critical discussion of their views, by outlining their respective views, and discussing their strengths and weaknesses as an account of dignity, in particular in the context of clinical ethics. Additionally, I identify the aspects of each view that I work to emulate in my own narrative-based account of narrative dignity, explicated in the following chapter.

A. David Luban’s Relational Human Dignity and the Law

I am going to argue for a relational view of dignity. I find the basic ingredients for such a view in some of David Luban’s discussion in “Lawyers as Upholders of Human Dignity (When They Aren't Busy Assaulting It).” Luban states that “to have human dignity” means “being the subject of a story,” and “honoring human dignity means refraining from overriding [their] commitments for paternalistic reasons” (Luban 2005, 838). Luban also suggests, perhaps inconsistent with the foregoing, that human dignity is “a property of relationships between humans—between, so to speak, the dignifier and the dignified” (Luban 2005, 817). As the title of the article indicates, Luban takes up these considerations in the context of the practice of law, but his account has far reaching philosophical implications. Moreover, the professional application to law has, as we’ll see, a promising mirror in the practice of medicine and clinical bioethics. In this section, I explain Luban’s view, take note of some important potential inconsistencies, and draw out the parts that are particularly powerful and exciting, and that are meaningful in developing my own framework of relational dignity.

Luban argues for his account in parts based on its metaphysical lightness. He takes himself to be responding to a long tradition in Western philosophy that grounds human dignity in autonomy. He suggests that “the philosophical identification of human dignity with autonomy is … wrongheaded” (Luban 2005, 817). He rejects the conception of human dignity as “a metaphysical property of individual
“humans,” along with any strong relationship between autonomy and dignity, noting that this fundamental kind of dignity can be a bit metaphysically mysterious. Moreover, Luban argues that even if we accept that human beings have universal dignity of this kind, then it’s not particularly helpful in understanding the moral features of the legal profession, nor, for our purposes, in directing medical decision-making. For if we agree with Luban that the metaphysical grounds of dignity are mysterious, then this may entail some difficulty in figuring out what dignity requires in practice. The most plausible accounts seem to attach dignity either to our humanity—whether we conceive of that as a biological category or a social category—or to a capacity like rationality, consciousness, or sentience. As we have seen, one the former interpretation, dignity is best suited to help explicate moral requirements in the broadest sense, that is, in terms of very general obligations or prohibitions. On the latter interpretation we quickly run the risk of encountering the limits of dignity in cases where the relevant capacity is undermined.

Luban draws on his experience in law to solidify a notion of dignity, which he then uses to further illuminate certain features of the legal landscape. One fundamental aspect of this notion of dignity is a narrative account of self. The very notion of an advocate, Luban argues, only makes sense if we think that people have a story that matters and deserve to be heard: “Once we accept that human dignity requires litigants to be heard, the justification of the advocate becomes clear” (Luban 2005, 819). Central to the importance of our story, is what Luban calls the “ontological heft” of human subjectivity (Luban 2005, 821). As a being with a perspective on the world, it is this perspective or subjectivity that is the grounds of our moral status. As such, violations of this perspective “fundamentally denigrates my status in the world” (Luban 2005, 821). A perspective does not prima facie seem like the kind of thing that is easily violated. But it is through this perspective that we have a lived experience of being in the world. And this experience becomes our story. When this story is not recognized, or treated as trivial, then the person is humiliated, where “humiliating people denies [them] their human dignity” (Luban 2005, 822). This means that dignity becomes not a metaphysical property that attaches itself to rationality or individuals, but rather a relational property that describes a dynamic between (at least) two people.

In this basic development of relational dignity we can see a number of important inconsistencies and other potential problems. For one, Luban explains that it is our perspective on the world, or our point of view, that grounds our moral worth and therefore gives us dignity. He clearly expresses this when he states that “having human dignity means, roughly, having a story of one's own” (Luban 2005, 821). Narrative accounts of identity have an extensive literature in the philosophy of personal identity. For now, I follow Luban in using the term loosely.
This idea is in tension with several other expressions of (the violation of) dignity. For instance, Luban notes that having one’s perspective trivialized “fundamentally denigrates” the status of that person (Luban 2005, 821). But if dignity is about the bare fact of having a point of view, then having others trivialize that point of view is not a fundamental denigration so much as a failure to appropriately respect a person. Moreover, we have seen that Luban also expresses human dignity as “a property of relationships between humans — between, so to speak, the dignifier and the dignified” (Luban 2005, 817). Here, the dignifier takes up with the person’s story in an appropriate way, thereby dignifying them. Here, then, Luban identifies dignity not as a fundamental feature tied to our having a perspective, but as an interpersonal making good on the content of this story. These are very different kinds of properties that are seemingly equivocated on. It’s not clear that this conflation can be resolved without doing damage to Luban’s theoretical intent. That said, identifying dignity as a relational property is an exciting move. It intertwines the very notion of obligation with the concept of dignity and centralizes the social aspect of dignity.

In rethinking dignity and its ties to rationality, we also have to rethink autonomy. It’s clear that autonomy is a kind of freedom, and that there are many different ways in which we can conceive of this. As Luban points out, the popular conception of freedom in the United States is a far reaching negative freedom, which Luban calls freedom of choice (Luban 2005, 826). Americans, he suggests, want to act in all matters without the interference of authority, which asserts itself in different— and on occasion contradictory—ways such as political libertarianism, religious fanaticism, second amendmentism, the anti-vaxx movement, anti-intellectualism, COVID myths, consumerism, and other such -isms and conspiratorial factions. This is a far cry from Kant’s conception of autonomy, which constitutes the very ability to formulate and will in accordance with the supreme authority of the moral law. Luban divorces his story-based relational dignity from autonomy, conceiving of the latter as a much narrower capacity. He argues that “Autonomy focuses on just one human faculty, the will, and identifying dignity with autonomy likewise identifies human dignity with willing and choosing. This, I believe, is a truncated view of humanity and human experience” (Luban 826). Dignity, by contrast, reflects a much broader range of our experience.

Autonomy remains, of course, an important capacity, but on Luban’s account it is not intrinsically connected to dignity in the way that Kant suggested. Autonomy can be violated in the familiar ways, by overwriting the agent’s own will and capacity for decision-making. When the undermining of autonomy is motivated by the best interest of the agent who is being infringed upon, this is paternalism. Of course, both the practice of law and medicine require that we avoid paternalism as much as possible. That is, we want to avoid infringing upon the freedom of others even under the supposition of their own best interests. People are, after all, free to make decisions that violate (some of) their interests. They have the dignity of risk. The
capacity for altruism and sacrifice. Moreover, there is more to people than their mere
wills, and as Luban states “Honoring someone's human dignity means honoring their
being, not merely their willing” (Luban 2005, 826). Our wills are only a part of the
totality of our being, and not always ideally suited to guide our lives. Our wills can
suffer under pathology, we can will based on a miscomprehension of relevant facts,
and we can will beyond our capacity. To respect someone's dignity means to respect
every aspect of their identity. This “includes the way they experience the world—their
perceptions, their passions and sufferings, their reflections, their relationships and
commitments, what they care about” (Luban 2005, 826).

We can see another important amalgamation of terms, namely those of point
of view, perspective, story, experience, and the breakdown of the latter feature, in
terms of passions, relationships, and so on. It's not clear what the relationship
between these terms is. In some places Luban uses “story” to refer to the experience
of events from one's point of view, something like the way a point of view camera
could record the story of one's life. This is the kind of understanding of one's life that
can be expressed in someone's personal testimony.²⁰ In other places, Luban seems to
have something more in mind when he talks about a person's story, such that it
doesn't merely include testimony, but desires, values, and preferences, and perhaps
important commitments and relationships as well. As before, it's not clear that these
various usages can be reconciled across the board. Luban's account stands in need
of a definite conception of story that makes clear its connections to perspective and
its relation to dignity. That said, “story” plays a vital role here that has the potential to
serve as a framework for analyzing the structure of a person's life, including their
testimony, values, preferences, and relationships.

Luban offers a central case as a means of illuminating his account of dignity,
namely that of Theodore Kaczynski, a.k.a. The Unabomber.

Case—The Unabomber

Theodore John Kaczynski was raised in Chicago. He was a math prodigy
whose father in particular seemed to have pushed for his academic success
(Chase 2012, n.p.). He entered Harvard University in 1958 at the age of 16, and
had seemed “a socially reserved genius” (Song 2012, n.p.). During this time at
Harvard, Kaczynski was part of a psychological study by Henry A. Murray, who
“conducted a disturbing and what would now be seen as ethically
indefensible experiment on twenty-two undergraduates,” which were
designed “to measure how people react under stress” (Chase 2000, n.p.). This
appears to have been motivated in part by the “Office of Strategic Services, the

²⁰ I use “personal testimony” to refer to the story we express about ourselves to others. Here, it
is meant to distinguish this concept from “legal testimony,” which is testimony in the context
of the court of law.
forerunner of the CIA,” which was intending to measure how well recruits hold up under interrogation (Chase 2000, n.p.). After his time at Harvard, Kaczynski “earned a Ph.D. in mathematics at the University of Michigan, becoming an assistant professor at the University of California, Berkeley in 1967” (Song 2012, n.p.). He resigned just two years later.


After the manifesto’s publication, David Kaczynski recognized his brother as the author. As a result, the FBI was able to apprehend him, nearly a year after his final bomb murdered Gilbert Murray, “president of the California Forestry Association” (Chase 2000 n.p.). While his manifesto had initially been received as profound, public opinion switched during his trial, where he was painted as insane (Chase 2000, n.p.). Ultimately, after being denied the opportunity to represent himself, Kaczynski was able to avoid the mental defense by pleading guilty, receiving “a sentence of life without parole” (Luban 2005, 828-9).

Pursuing an insanity plea may seem like a reasonable course of action in these circumstances, especially considering the possibility of the death penalty. And indeed, Kaczynski’s lawyers hoped to avoid the death penalty by these means. However, Kaczynski knew that this plea would be used to undermine the legitimacy of his manifesto. He therefore rejected this option and refused psychological evaluation. Eventually his lawyers tricked him into an evaluation that was admitted to the court. As Luban explains, “the manifesto he wrote is a coherent work of social theory, certainly as coherent as many essays I have read by respectable philosophers. And his motivation for wanting to avoid the mental defense is equally coherent, and expressed with substantial eloquence” (Luban 2005, 829). To overwrite Kaczynski’s wishes, even when motivated by considerations for his own best interest, is both paternalistic and humiliating. That is, to be publicly recognized as insane and have one’s life’s work and perspective undermined constitutes the dismissal of one’s story. Whatever our ultimate judgment about Kaczynski, it is clear that his lawyers’ treatment of him was undignifying.

This case demonstrates an important virtue of Luban’s account. That is, we might assume that the role of the lawyer in the legal system is to provide the best possible defense for their client. And we might think that in respecting his wishes, Kaczynski’s lawyers would have failed their professional responsibility. This is, however, in discordance with the way Luban understands the role of the lawyer. For
Luban, the lawyer is an advocate in the truest sense of the word. They advocate for the defendant, but this doesn’t simply entail mounting the best defense at whatever cost. Rather, this means presenting the story of the defendant in a manner that is appropriate to the context of the court. An advocate is an expert on the law and the courtroom. They understand the necessary jargon, specifics of the law, courtroom decorum, and can differentiate between what is legally relevant and not. This means that while an advocate is made necessary by the unique features of the court, the goal of the advocate is representative, where this refers to the legal goals of the person they are representing. Similarly, in medicine the goal of the physician is sometimes seen as doing everything possible to meet the medical interests of the patient. But this would entail excess medical paternalism. The physician is an expert on the body, pathology, and treatment. They understand symptoms, diagnostics, and possible treatments. But their goal too is to navigate the healthcare environment according to the needs and goals of their patients. As Luban states, “Human dignity consists in having one’s own story to tell. It consists as well in not subsuming one’s own point of view—one’s own story—to the impersonal needs of the legal system” (Luban 2005, 837). This holds in medicine as well. Moreover, we can see a mirror of Kant’s dictum here, in that one should never subsume the story of another for purposes that are not theirs, but should always allow them to tell it as they choose. This is, of course, a general principle. A more specific and practicable account of its application, especially outside of the law, requires developing the key concepts noted above, in particular “point of view” and “story”, as well as the relation between them.

It’s important to note that the notion of non compos mentis is not identical to the status of being incapacitated in the context of medicine. That said, there is in Luban’s treatment of Kaczynski’s case an acknowledgement of the idea that capacity can apply differently to different aspects of someone’s decision-making. Even if we think that Kaczynski was non compos mentis with respect to his terrorist activity, Luban recognizes Kaczynski’s manifesto, “Industrial Society and Its Future,” as “a coherent work of social theory” (Luban 2005, 829). This suggests that, in terms of the expression of his ideals, Kaczynski was competent. Kaczynski’s reasoning for rejecting the mental defense was also coherent, as he thought that this would discredit his manifesto and to all the world make him out to be, in his own words a “grotesque and repellent lunatic” (U.S. v. Kaczynski 2001, n.p.; Luban 2005, 828-9). Ultimately, Luban argues that Kaczynski’s story with respect to his desire to decline the psychiatric evaluation and mental defense were coherent, and for his lawyers to prevent Kaczynski from being represented accordingly is undignifying (Luban 2005, 829).

There are important questions we can raise at this point. For one, if a person is found to be legally incompetent and their story lacks coherence, how ought their advocate respond? Do they fall back to the best legal defense standard? What if a defendant has stable preferences over time that indicate otherwise? In other words,
what is the role of the fully legally incompetent person's story in their defense, if any? Luban's conclusion regarding dignity is instructive, so I include it here at length, omitting only some of the law-specific sections:

At this point we are in a position to draw some preliminary conclusions about what it means to have human dignity, as the concept has emerged so far. It means, first, being the subject of a story, no matter how humdrum or commonplace that story is. And honoring human dignity means assuming that someone has a story that can be told in good faith, hence listening to it and insisting that it be told. Second, we have learned that to have a story means more than to be an autonomous chooser. It means being the subject of experience, and it means existing in a web of commitments, however detestable or pathetic those commitments may be. And honoring human dignity means refraining from overriding those commitments for paternalistic reasons. Third, ... having human dignity means being an individual self who is not entirely subsumed into larger communities. ... Underlying all these themes, I think, is a single root idea. Whatever the metaphysical basis of human dignity—indeed, whether or not human dignity even has a metaphysical basis—at the very least honoring human dignity requires not humiliating people. Indeed, I would propose this as a condition or criterion that any theory of human dignity must satisfy: it must entail nonhumiliation as a theorem. (Luban 2005, 838-9)

Central to this understanding of dignity is understanding persons as beings with a perspective on the world. As we move through life, this locus of experience develops a narrative that isn't merely self-centered—it constitutes the self. Dignity is relational, because it requires that others recognize us as beings with a story, and afford this story a proper place. For Luban's purposes, this concerns the proper place and presentation of one's story in the context of the court. For our purposes, this concerns the proper place of one's story in (surrogate) medical decision-making. What is held in common is that the proper place of this story is front and center. It is the job of the professionals—whether lawyers, physicians, psychologists, pastoral carers, or bioethicists—to translate this story in a way that suits the professional environment and coheres with the agent's ends, rather than subvert the story to other purposes.

The conclusions Luban draws based on the account are intuitive, and they are able to explain a number of intuitions we have about our lives, in particular in the context of law and medicine. One of the fundamental problems that Luban highlights is the historic relation between dignity and autonomy. As we have seen in our discussion of universal dignity, a close conceptual tie between dignity and autonomy entails the fundamentality of rationality in the ascription of moral status.
Luban is able to avoid this while preserving the concept of dignity. This allows us to make claims about dignity and paternalism, without requiring autonomy. Metaphysical accounts of dignity are a bit mysterious. Moreover, they can (and do frequently) raise difficult questions about the limits of dignity, for instance in people with disabilities, at least at times leading to morally questionable conclusions. Luban’s account also makes clear the connection between decision-making and dignity. For the individual making decisions about themselves, it’s about how they situate their choice within the framework of their life story. Following Luban’s motivation of the view, we can see that it makes fewer metaphysical demands, and provides a good fit with the picture of humanity that has been emerging in Western thought over the last few decades. It respects the social nature of our (moral) lives and the centrality of storytelling to our conception of self. It is able to make sense of a lot of the wrongs we see in the cases he discusses, and seems to have this power for medical cases as well. As such, relational dignity appears to fit with at least part of our folk understanding of dignity.

Central to Luban’s understanding of dignity is the notion that a person has a story worth telling. One thing to note is the idea of a story worth telling fits well in the context of the law and legal representation. The courtroom is, after all, the designated place to share one’s story as it pertains to one’s membership in society. That is, in a certain sense, the courtroom is about a very particular form of storytelling. This doesn’t translate neatly to health care. What does it mean for this patient’s story to be told in good faith? We can exemplify this problem by looking at a case.

Case—(How) Do We Choose Our End?

The patient is a 46 year old female patient. She came in “feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. They did a bone-marrow biopsy and she was diagnosed with acute myelomonocytic leukemia. The oncologist proposed a course of induction chemotherapy, followed by consolidation chemotherapy, and finally a bone-marrow transplant. The survival rate of this course of treatment is about 25%. The survival rate of no treatment is about 0%. The oncologist met with the patient to inform her of the diagnosis and had made plans to begin induction chemotherapy that afternoon. This enraged the patient, who refused treatment. When the patient saw their treating physician several days later, they remained steadfast in their refusal for treatment, with limited support from their family. A couple of weeks later, the patient came to the physician requesting barbiturates to aid in sleep.

---

21 Luban defines paternalism as “interfering with someone else's liberty for their own good” (Luban 2005, 824).
While barbiturates can be a powerful sleep aid, their non-prescription use can also result in death. In conversation with the patient, it becomes clear that they are planning to use it as a sleep aid, but that they are also aware of its secondary use, and wish to have enough of the medication to be able to commit suicide. By law, the physician is banned from providing assistance in patient suicide. The physician must choose whether or not to assist the patient. (Originally from Quill 1991a)

Approaching this case from Luban’s perspective, the first questions we may ask are, (1) how can the patient’s story be represented accurately, and (2) what does dignity demand in this case? The former points to a problem in translating the framework to an area outside of the legal field. Luban’s concern is with legal representation in the court by way of an advocate, where this representation concerns the literal representation of the person’s story to the court, in court-appropriate ways. In this case, the patient is not being represented, nor does their situation require the lay-to-legal or lay-to-medical translation of a story. In fact, they seem to grasp their situation well and are able to advocate for themselves in a medical context. It is therefore unclear what the requirement to represent this patient’s story accurately requires in this context.

Furthermore, in considering the decision the physician is asked to make in this case, given the fact that Luban’s notion of dignity befits a legal framework, I am inclined to think that the legal prohibition against physician assisted suicide weighs heavily here. This is further supported by the unclear demands of story-based dignity. That is, whether or not the physician chooses to assist the patient in their suicide does not directly seem to change whether or not their story is recognized, as it does not change how we see the patient and understand their situation. To make this claim tenable, contrast this case with that of Kaczynski, whose lawyers attempted to fundamentally alter the public presentation of his motives and intentions. He came to be perceived, not as an intelligent and committed activist fighting for a better future, but as an insane, loner, radical terrorist. In a medical setting, we already exist in a context of claims and obligations that require the general recognition of a person’s story. Without greater specificity as to the nature of the story or the demands of story-based dignity, the account is insufficiently action-guiding in a medical context.

What is vital is that we have a view of dignity that can do the heavily ethical lifting required, without making undue metaphysical demands. However, this cannot come at the cost of conceptual clarity. This is where Luban’s account is lacking. First, the account is not sufficiently clear on what it means to be “the subject of a story” (Luban 2005, 838). What is required for one to be the subject of a story? And what is a “story” in this context? Luban expands on this, noting that “to have a story means more than to be an autonomous choosers. It means being the subject of
experience, and it means existing in a web of commitments“ (Luban 2005, 838). This makes clear the dissociation of dignity from autonomy. However, the extent to which dignity is “more” than autonomy is not clear. Is there conceptual overlap that dignity exceeds or are they entirely disjointed? Is being the subject of experience the same as having a story, or is the former a necessary condition for the latter? What are the relevant commitments and how do these connect to our story and dignity?

Second, we need a clear account of the nature of a story. “Story” is a helpful term, because it very quickly introduces what the view understands as essential to the human experience. It immediately contrasts itself with other views, pointing to subjective experience, rather than sentience or rationality as the source of considerability. The ease with which the term primes for comprehension is due to its status as a metaphor. A story is an (auto)biographical account. It is an artifice — curated, crafted, polished, revised. It can recount someone’s experience, but it’s not the same as that person’s lived experience. As a result, it’s also unclear whether all and only human beings have a story. So beyond its initial usefulness, the term stands in need of careful definition.

Third, the account lacks sufficiently developed related moral concepts. Luban explains that “honoring human dignity means refraining from overriding those commitments for paternalistic reasons” (Luban 2005, 838). Unless this account of dignity is meant to do work only in the context of the law, or perhaps journalism, there must be more to dignity than telling someone’s story. What exactly does it mean to respond appropriately to someone’s story? Furthermore, Luban understands paternalism to mean “interfering with someone else’s liberty for their own good” (Luban 2005, 824). This is a very general definition. What is someone’s liberty, and what entitles them to it? What if someone lacks this kind of liberty? Is paternalism a violation of dignity or of autonomy? The Kaczynski case fails to illustrate this sufficiently, because we can interpret the legal team’s overwriting of his wishes as both a violation of his dignity and as a violation of autonomy, because it seems that he was capacitated for the relevant decisions. What does respecting someone’s story means with respect to the morally indefensible parts, such as Kaczynski’s ideologically supported terrorist activities? Or someone’s deeply unsettling, sorrowful, or harrowing story?

As we have seen, Luban is vague in places where it matters, and it’s not clear that the account can be made coherent without doing some damage to the overall structure of his view. Nevertheless, the account contains some exciting elements that have inspired the framework of relational dignity that is central to this project. Dignity as a relation property, the centrality of the social nature of our moral lives in recognizing dignity as interactive, narrative as the expression of the structure of a person’s life and the grounds of dignity — these are important elements that can do profound moral work. I come back to these in arguing for my own account of relational dignity.
B. Suzy Killmister’s Dignity and Personal and Social Values

In her *Contours of Dignity* (2020a), Suzy Killmister offers a full account of her theory of dignity. Like Luban, she resists a universal account of dignity. In particular, she contrasts her view with Rosen’s explication of dignity as an “Inner transcendental kernel” (Rosen 2012, 9, quoted in Killmister 2020a, 5). She does this for three reasons. First, because conceiving of dignity as a property that is conferred does the same moral work. Second, because metaphysical dignity will reduce to some other property, such as rationality. And finally, because such a reduction ultimately risks excluding those who lack it (Killmister 2020a, 5-6). Killmister understands dignity as a property that is conferred (Killmister 2020a, 5). In particular, dignity is conferred through a recognition and respecting of the relevant personal or social norms. (Killmister 2020a, 12, 22-24). As a result, dignity can also be lost or destroyed (Killmister 2020a, 10-11). Killmister views dignity as a “tapestry,” which comprises “several distinct but complementary interwoven strands” (Killmister 2020a, 3). It will be useful to start by looking at these strands of dignity, before discussing the kinds of damage that dignity can suffer according to Killmister. I conclude this section by identifying some limits with respect to Killmister’s account.

**Three Kinds of Dignity**

Killmister distills three desiderata that a concept of dignity must meet in order to “accommodate the core uses to which the concept is put in everyday discourse” and “demonstrate what moral work it is capable of” (Killmister 2020a, 13, 14). First, the view must make clear that and how “dignity has something to do with the respect people command” (Killmister 2020a, 14). Second, it must account for the ways in which “dignity is a variable quality” (Killmister 2020a, 15). Third, it must allow that “dignity is the kind of feature that can be damaged, or persons can be stripped of” (Killmister 2020a, 15). In order to meet these desiderata while avoiding the difficulties raised by the universal account of dignity, Killmister differentiates between three strands of dignity, namely personal, social, and status (Killmister 2020a, 21). She explains that people have personal dignity “in virtue of taking ourselves to be subject to a certain kind of norms” (Killmister 2020a, 24). For instance, I may have a norm for being independent. I go to meet my friend in a coffee shop and order a drink. I come to find out that I have forgotten my wallet, and need to ask my friend to spot me. This undermines my norm for independence, wherefore I experience embarrassment and feelings of indignity. Social dignity functions very similarly, but in terms of social norms, i.e. the norms of the relevant community or communities. For instance, Pam is a woman who was brought up in a conservative religious community where a particular form of modest dress is the norm. They return to their hometown after
several years away, and walk around the grocery store in their typical attire. The local population perceives these fashions as immodest, and judge Pam accordingly. This “lowers [her] in the eyes of [her] peers” (Killmister 2020a, 50). This means that Pam suffers a social indignity. This is true whether or not Pam experiences this judgment or is herself affected by it. Status dignity, by contrast, concerns the norms that are attached to a function or category, for instance the norms attached to the office of President, the status of celebrity, or the species of human. We can imagine a Kardashian being humiliated if she enters a public space and no one oohs and aahs. Being the subject of public admiration may well be a norm for a celebrity influencer.

Killmister explains that the difference between these kinds of dignity can best be explicated in terms of the first desideratum, namely by answering the questions “1) How is dignity constituted? 2) What form of respect does dignity command? And 3) whose respect does dignity command? Here, Killmister relies on Stephan Darwall’s distinction between appraisal respect and recognition respect (Darwall 1977, cited in Killmister 2020a, 21). Appraisal respect “is analogous to esteem … [and] is directed at the “whole self’ of its object” while recognition respect “consists in ‘a disposition to weight appropriately in one’s deliberations some feature of the thing and act accordingly’” (Killmister 2020a, 21, quoting Darwall 1977, 38).

Killmister explains that “Both personal and social dignity … call for appraisal respect” (Killmister 2020a, 22). The degree to which I live up to the norms to which I hold myself and to which my community holds me constitute my moral standing, in terms of the respect I have for myself and that others have for me. In terms of our examples above, when I have to ask my friend to lend me the money for the coffee, this affects my self-respect, and this is true regardless of my friend’s attitude concerning my request (Killmister 2020a, 48-9). And in Pam’s situation, it is not merely her attire that is judged as falling short of the fashion standards of her hometown community. Rather, she is judged as failing to uphold the norms of the community, and as being immodest.

Status dignity is different, “Because it is held in virtue of a category membership in which commands respect, the relevant notion is recognition respect” (Killmister 2020a, 23, original italics). Status dignity requires that we recognize the relevant kind of membership and respond according to the norms that this dictates. That is, we should recognize the Kardashians as being famous, and therefore entitled to the trappings of fame. This requires the aforementioned oohing and aahing. However, failing to publicly admire the Kardashians does not criticize or undermine their full personhood, but only affects their status qua celebrity. This means that status dignity “does not come in degrees” (Killmister 2020a, 55). Either someone has their membership in the relevant category recognized, or they do not.

In her earlier work, it seems that Killmister understands social dignity and human dignity as a kind of fall back option, in case personal dignity ceases to hold. In “Dignity: personal, social, human” (2017), she holds that the relevant standards are in
the first place personal. We determine for ourselves what is acceptable and what is not, because each person has standards for themselves with respect to the acceptable actions and behaviors of themselves and others. As an example of how these values function as norms with respect to dignity, consider the following case.

Case—Social Media Aunt

Lidia’s mom, Nora, is in the hospital. She's currently sedated, but receiving select visitors. On her second day there, Lidia is with her mom in the morning, then goes home for the afternoon when her aunt, Nora's sister, comes to visit. That evening, Lidia sees that her aunt has posted pictures of her mom in the hospital bed on social media. Lidia is upset, because her mom is a vain and private person. Her mom never leaves the house unless she is in full make-up, and she does not have any social media, because she does not want to make her private life public in any way. Lidia messages her aunt, asking her to take the photos down. When the aunt refuses, Lidia contacts the hospital to request that her aunt is no longer permitted to visit her mom.

This case may at first seem like a superficial family conflict. But when we think about it in terms of Killmister’s account of dignity, we can see that this case strikes at the heart of Nora’s personal values, and therefore their dignity. First, as a (1) person who is (2) a member of various communities, Nora has moral standing, and we should take into account the way her family’s actions affect her. Second, we can see that Nora’s situation leaves her vulnerable to disrespect. In fact, her sister is clearly unwilling to uphold Nora’s values. Finally, through Lidia’s efforts, Nora’s dignity is now protected, even if it has been affronted by having the pictures accessible on social media.

When personal standards are unavailable, we ensure universality by defaulting to social standards. Here, the standards society has set with respect to acceptable actions and behaviors toward ourselves and others become authoritative (Killmister 2017, 2077). For instance, in the case of a comatose patient for whom we lack any and all identifying information and for whom we have no indication of their values, we can default to social values to guide decision-making.

In Contours of Dignity (2020a), the account lacks this kind of ranking among the strands of dignity. These different norms can exist and be authoritative at the same time. Moreover, it is important to note that for Killmister these values need not be reflective. She notes that “personal dignity can be violated if an agent is made to do something she judges to be debasing ... or if she is made to do something she is disposed to respond to with lowered self-regard, irrespective of her reflective judgment” (Killmister 2020a, 44).
What about human dignity? Killmister considers human dignity to be a special kind of status dignity. This means that “we have human dignity in virtue of our status as humans, and what our human dignity commands is the recognition respect appropriate to that status” (Killmister 2020a, 129). This requires us to answer an underlying question, namely, What is a human being? Here, it is important to draw the distinction between natural kinds and social kinds. There is, of course, the biological explanation of what it means to be a human, which is a natural kind. Part of the motivation for Killmister’s account is the exclusionary nature of metaphysical accounts of dignity. She considers the general response to this objection, namely that dignity isn’t grounded in any one individual’s rationality, or some other such feature, but instead in the natural kind that is a human being. Killmister rebuttals that natural kinds cannot solve the issue of exclusion (Killmister 2020a, 18). To ground dignity in natural kinds in this way is to commit a kind of inductive fallacy. It says that the grounds of dignity is property x, and human beings generally have property x, therefore all human beings have dignity. However this is clearly false if property x is a prerequisite of having dignity. It would be roughly analogous to argue that the grounds of vision is the optic nerve, and human beings generally have an optic nerve, therefore all human beings have vision. It is clear in this case that we cannot simply extend the feature (dignity/vision) to all members of the natural kind (human), when the underlying property (rationality/optic nerve) is not universally present in the natural kind.

Since this avenue of guaranteeing human rights is untenable, Killmister instead grounds human rights in the social kind that is human being. Social kinds are a familiar category, and include things such as “money, royalty, nation-states, and citizens” (Killmister 2020a, 101). Killmister explains that different conceptions of what it means to be human among different communities effectively gives rise to different social human kinds that may entail different kinds of obligations (Killmister 2020a, 130). Moreover, “a global variant [of the social human kind] has also emerged” (Killmister 2020a, 130). What does it mean to be human in this sense? Killmister suggests that to be human is “incompatible with being raised merely to provide organs to others,” is “to be entitled to a name,” and “to be grievable” (Killmister 2020a, 132, 133, citing Butler 2006, italics removed). In essence, Killmister holds that human dignity comes out of our “membership in the human community,” with all of its respective norms (Killmister 2020a, 35). She considers two accounts of social kinds to ground her view. The first is that proposed by John Searle, who holds that, in terms of social kinds, “X counts as Y in context C” (Killimster 2020a, 134, quoting Searly 1995, 2010). This account works as follows.
The logical structure is that we must treat being human as a status, like being private property, being a secretary of state, or being married. In the formula “X counts as Y in context C”, the Y term is “human being”; so if you qualify as a human being, you are automatically guaranteed rights . . . . [T]he X term is simply a set of biological facts that constitute being a member of our species. To satisfy those conditions is to count as a human being . . . and as a human being the bearer of rights. (Killmister 2020a, 135-6, quoting Searle 2010, 181-2)

She also considers Ásta’s conferralist account of social kinds, which requires the specification of a list of categories, including the coferend property, who and what does the conferencing, when, and the base property. Killmister provides content to these categories as specified below (Killmister 2020a 138, referencing Ásta 2018, 22).

<table>
<thead>
<tr>
<th>Ásta’s Category</th>
<th>Killmister’s Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conferred property:</td>
<td>Bearer of human dignity</td>
</tr>
<tr>
<td>Who [does the conferring]:</td>
<td>The global community</td>
</tr>
<tr>
<td>What [does the conferring]:</td>
<td>Attitudes and behavior acknowledging the norms</td>
</tr>
<tr>
<td></td>
<td>associated with human dignity</td>
</tr>
<tr>
<td>When:</td>
<td>Ongoing</td>
</tr>
<tr>
<td>Base property:</td>
<td>Membership in the species ‘homo sapiens’</td>
</tr>
</tbody>
</table>

My concern here is two fold. First, if we accept that human dignity is tied to the social kind of human being which is grounded in membership in the global human community, then to be a human being and therefore to have human rights is a contingent and malleable feature. This raises a number of questions. What is the human community? How has this community come to be? And what are the relevant social norms and practices? More specifically, it seems that the global human community has arisen out of a centuries long process of globalization, facilitated through colonialist and imperialist forces. This raises an issue concerning the propriety of the dominant values. Furthermore, it seems that this excludes certain groups of people from the realm of human rights. We can think, for instance, of uncontacted tribes. Part of what might motivate the globalized world to respect their isolation is the right to autonomy. But if they are not a part of the human community, then it’s not clear we can make sense of this demand. Additionally, we can wonder about the extensionality. Killmister raises this potential, noting that “a social constructivist approach must concede the possibility that the boundaries of the human could shift” (Killmister 2020a, 139). Killmister cites legal cases arguing for
the inclusion of great apes, and the development of artificial intelligence (Killmister 2020a, 139-40). So depending on how we approach other species with respect to their relation to us as human beings, the category of human being may expand to include great apes and dolphins. And we may think that the expandability is a feature, not a bug. But why do we want great apes to have human rights?

Killmister suggests that the human rights discourse has helped us recognize its universality, so that now it’s a largely settled matter. She explains that “the practice of human rights has helped determine who the bearers of human rights are, and it is now a relatively settled feature of the practice that all homo sapiens are bearers of human rights, and hence members of the human kind” (Killmister 2020a, 142). But does talk weigh more heavily than actions? As we’re barreling toward climate catastrophe, it looks like the northern hemisphere is fully prepared to let the global south drown or burn—perish. As imperial nations creep ahead on climate change issues, they are also continuing to stack the deck against the imperialized by settling them with the worst consequences of climate change all the while building the apparatus to restrict the flow of climate refugees.22

It seems that in evaluating the actual global perception of certain categories of people, that we fail to include them in the social kind of human being. This makes the social kind worryingly adaptable to global forces of marginalization. Killmister recognizes that “Systematic denial that certain kinds of people are entitled to be treated as human beings carries the very real threat that the boundaries of the human will shrink to excuse such people” (Killmister 2020a, 155). And this is a very real threat. Have we not previously decided against the inclusion of people with a different skin color? Similarly we may consider the way the world turned its back against Jewish refugees in the lead up to and during the Shoah, and the treatment of disabled people during the era of institutionalization. And this is not merely a concern when surveying the history of oppression, but one that is already visible in the current dehumanization of people who struggle with homelessness, refugees, and immigrants (Killmister 2020a, 156). A particularly troubling feature of the view is that it only allows us to make sense of the wrongs of this kind of exclusion either in retrospect or in anticipation thereof. Once a group is excluded, they no longer warrant recognition respect, and they are no longer entitled to the kind of treatment that befits human beings.

Second, both Searle and Ásta ground their conception of social kinds in the natural kind of human being, or the properties associated with this natural kind.

22 See, for instance, Andrew Baldwin, Chris Methman, and Delf Rothe’s introductory article entitled “Securitizing ‘Climate Refugees’: the Futurology of Climate-Induced Migration” (2014), as well as the other articles in the special issue of Critical Studies on Security. Additionally, see Paul J. Smith’s “Climate Change, Mass Migration, and the Military Response” (2007), and Betsy Hartmann’s “Rethinking Climate Refugees and Climate Conflict: Rhetoric, Reality and the Politics of Policy Discourse” (2010).
Here, we can ask what it is about this natural kind or about these properties that substantiates the social kind. The problem is that natural kinds are a complicated concept, because it’s unclear what defines them. Genetics? Species? These are not clean categorizations. So what are the relevant features that determine membership in the natural kind such that they substantiate the social kind? Here, we run the risk of falling back to features like rationality. This also explains the potential extensionality of human kind, because we recognize that great apes and dolphins and potential extraterrestrials are rational. In other words, a conception of social kinds that references natural kinds likely ends up in the same predicament as a direct use of natural kinds. Perhaps one way to solve this is to make a Strawsonian move, and define the social kind of human being as one who appropriately solicits human being recognition respect.\(^{23}\) This, though, leaves open what makes this solicitation appropriate, and also brings us back to the problem of exclusion.

**Three Kinds of Damage to Dignity**

Two of the three desiderata have to do with the fragility of dignity. As Killmister notes, dignity “can be damaged, and even destroyed, by the actions or inactions of others” (Killmister 2020a, 39). There are three kinds of damage to dignity that Killmister specifies, namely violations, frustrations, and destruction. Each of the three kinds of dignity can suffer this kind of damage. We have already seen some of these kinds of damage in the preceding examples. Violations of personal dignity occur “when an agent is forced to transgress her own dignitarian norms, or when she is prevented from upholding those norms” (Killmister 2020a, 47). When I’m forced to borrow money from a friend against my own deeply held values, this undermines my self-respect. Frustrations of personal dignity means that we are unable to participate in the activities we find personally valuable or ennobling, such as reading or creating art. Kilmister offers an instructive example here. “Consider an individual with a physical disability, who takes pride in preparing her own meals. We can say of such a person that she has a dignitarian norm of independence” (Killmister 2020a, 16). In the event that this person is moved to a care facility where she is no longer allowed the opportunity to prepare her meals, this constitutes a frustration of her dignity. That is, while this is an impediment on the realization of a dignitarian norm, the inability to prepare food is not experienced as debasing in the way required for a violation of dignity (Killmister 2020a, 61). And the destruction of personal dignity means that the foundations of our lives as a being that has norms, is destroyed. “To destroy someone’s personal dignity, then, is to render her such that she no longer takes herself to be subject to dignitarian norms” (Killmister 2020a, 63). Examples of this

---

\(^{23}\) See P.F. Strawson’s “Freedom and Resentment” (1962), among other works.
include the results of torture, extreme pain, and prolonged solitary confinement (Killmister 2020a, 64).

Social dignity can similarly be damaged, where violations are of the kind that “lowers one in the eyes of one’s peers” (Killmister 2020a, 50). Social dignity frustrations prevent one from participating in actions that are socially ennobling, such as being properly recognized for one’s achievements or contributions. Killmister likens the destruction of social dignity to excommunication, as it removes someone from the norms of the community (Killmister 2020a, 66). This looks a lot like Iris Marion Young’s understanding of marginalization. In “Five Faces of Oppression,” she explains that this “is perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation and even extermination” (Young 1990, 53). Young emphasizes the marginalization of people with public dependency, such as the elderly and people with disabilities, and Killmister takes note of people struggling with homelessness (Young 1990, 54-5, Killmister 2020a, 67).

Status dignity is different, insofar as it’s an all-or-nothing category of dignity. In other words, someone either has a particular status or they do not, and this does not admit of degrees. Status dignity is frustrated when someone is denied “the opportunity to receive the recognition respect they are due” (Killmister 2020a, 62). It is violated when someone is treated as beneath their status (Killmister 2020a, 70). Finally, status dignity is destroyed when someone is excised from the relevant category that connotes the status. That is, “to have one’s status dignity destroyed is to be removed from a social category, and hence no longer entitled to the forms of recognition respect membership entails” (67). Killmister provides a helpful chart that indicates how the three different kinds of dignity can be damaged. I have reproduced it on the next page in Table 1 in an expanded form, with the forms or consequences of the damage as well as examples.

**Dignity and Claims**

On Killmister’s account, dignity is about the norms that are generated either by ourselves, our community, or are attached to some status. However, norms can conflict. While fame might entail a to-be-fawned-over norm, my self-respect might demand that I don’t fawn over others. So what are the limits of respect? First, there might be legal limits to how we respond to certain norms. That is not to say that legal limits must always be taken as absolute, especially in the case of unjust laws. But the legal frame in which we’re operating is relevant to how we approach the relevant norm. Second, there are moral limits to respect. Killmister explicates these limits in terms of the claims we have on one another. Here, Judith Jarvis Thomson’s famous violinist case from her, “A Defense of Abortion” (1971), is instructive.
Table 1. How Dignity Can Be Damaged

<table>
<thead>
<tr>
<th></th>
<th>Personal Dignity</th>
<th>Social Dignity</th>
<th>Status Dignity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Violated</strong></td>
<td>Be forced to do something personally debasing</td>
<td>Be forced to do something socially debasing</td>
<td>Be treated contrary to norms attached to your social class</td>
</tr>
<tr>
<td></td>
<td>Undermines self-respect (48)</td>
<td>“[L]owers one in the eye’s of one’s peers” (50)</td>
<td>Demeaning treatment (56)</td>
</tr>
<tr>
<td></td>
<td>Stripsearches in prison (49)</td>
<td>“Public shaming” (50); Comatose person left naked in hospital hallway (52)</td>
<td>A celebrity being treated as a nobody (56); segregation (58-60)</td>
</tr>
<tr>
<td><strong>Frustrated</strong></td>
<td>Be prevented from doing something personally ennobling</td>
<td>Be prevented from doing something socially ennobling</td>
<td>Be excluded from spaces in which you have opportunities to receive respectful treatment</td>
</tr>
<tr>
<td></td>
<td>Blocks personal pride (61)</td>
<td>Blocks social pride (61)</td>
<td>Denies opportunity for recognition respect (62)</td>
</tr>
<tr>
<td></td>
<td>Prisoners being disallowed to access books or create art (61).</td>
<td>Being prevented from participating in a graduation ceremony (62)</td>
<td>POC’s systemic inaccess to positions of public power (62-3)</td>
</tr>
<tr>
<td><strong>Destroyed</strong></td>
<td>Cease to hold yourself to dignitarian norms</td>
<td>Cease to be held to social dignitarian norms</td>
<td>Cease to hold a status for which norms of respectful treatment apply</td>
</tr>
<tr>
<td></td>
<td>Annihilates of self and meaning (64-5)</td>
<td>Expels “from the shared norms of the community” (66)</td>
<td>Removes “from a social category” (67)</td>
</tr>
<tr>
<td></td>
<td>Loss of humanity due to torture or long-term isolation (63-4)</td>
<td>Homeless people in the United States (67)</td>
<td>Slavery’s designation of the person held in slavery as less than human (68)</td>
</tr>
</tbody>
</table>

24 Original table from (Killmister 2020a, 71). Consequences and examples added. Note that all in-table citations refer to this source but are only indicated with page numbers to save space.
Case—*The Violinist*

You wake up in the morning and find yourself back to back in bed with an unconscious violinist. A famous unconscious violinist. He has been found to have a fatal kidney ailment, and the Society of Music Lovers has canvassed all the available medical records and found that you alone have the right blood type to help. They have therefore kidnapped you, and last night the violinist's circulatory system was plugged into yours, so that your kidneys can be used to extract poisons from his blood as well as your own. The director of the hospital now tells you, “Look, we're sorry the Society of Music Lovers did this to you—we would never have permitted it if we had known. But still, they did it, and the violinist now is plugged into you. To unplug you would be to kill him. But never mind, it's only for nine months. By then he will have recovered from his ailment, and can safely be unplugged from you.” (verbatim from Thomson 1971, 48-9)

The violinist may have personal norms in favor of reaching their health goals and continuing their life, and their public image may entail social norms to that same end. Even the various relevant statuses as a famous violinist, a citizen, a human being—these all support returning the violinist to health. However, as Thomson convincingly shows, none of these norms generate a *claim* on the person such that the use of their body is obligatory, or—without consent—permitted. And they are neither legally nor morally required or obligated to consent to the use of their body in this manner.

The case of the violinist is of course fictional and borderline futuristic. Killmister offers a different case that demonstrates how agents may lack a sufficient claim against having their dignity violated.

Case—*The Entitled Misogynist*

The Entitled Misogynist: Barry has been brought up to believe that men can expect to receive the attention and affection of women, and that the inability of a man to secure this attention and affection makes him contemptuous. Barry thus has the following personal dignitarian norm: it is debasing to be denied the attention and affection of any woman from whom it is sought. On his morning commute Barry's eye is caught by Bonnie, sitting on her own reading a book. He approaches her, and expresses his interest in receiving her affection. Bonnie ignores his advances, and continues to read her book. Barry then experiences a deep feeling of personal shame. (verbatim from Killmister 2020a, 78-9)
Reading this case, we don’t want to in any way validate the claim Barry is making on Bonnie. In fact, we are likely inclined to say that Barry has no claim on Bonnie. But, Killmister recognizes, we are hard pressed to conclude that Barry suffers no indignation. A claim can either be entirely absent or insufficient (Killmister 2020a, 80). Either way, the person making or appealing to the claim suffers indignation, but only in the case of an insufficiently strong claim does the violation of dignity constitute a wrong, albeit a justifiable wrong (Killmister 2020a, 80). Such a violation, Killmister argues “ought to be accompanied by regret” (Killmister 2020a, 80). We can see that Barry has no claim on Bonnie, and so while his personal dignity may have been violated, and this may have been a harm to him, Bonnie did nothing wrong in rebuffing his advances. She does not owe it to him, in any way, to make good on the norms that he (or his upbringing) has created for himself.

We can briefly apply this to two different cases. The first case concerns Karen, a patient who has come in complaining of chest pain. Her assigned physician is Imani, a Black American woman. As soon as Imani introduces herself, Karen becomes indignant. She refuses to shake hands and quickly requests a different doctor. When Imani asks why, Karen informs her that she wants to be treated by a white doctor. Here, Karen is clearly expressing a personal norm, and to refuse to make good on this request would be to violate her dignity (Killmister mentions a similar case in (Killmister 2020a, 83-4). This raises the question whether Karen has a claim on Imani to step aside. In general, healthcare operates under the assumption of the claims the patient has on the system and staff to be provided with care. However, this claim has no bearing on the patient’s health-related goals and treatment. The request was not motivated by, for instance, an interest in a second opinion, but only by the racist attitude of the patient. Killmister explains that social kinds can also be hierarchical kinds, which can express oppressive relationships namely those of “privileged and oppressed” (Killmister 2020a, 112, citing Mills 1997, italics removed; see also Young 1990, 42). “For a claim against having one’s status dignity violated to be valid, upholding it must not perpetuate or exacerbate the oppression of others” (Killmister 2020a, 112). This means that Imani has no obligation to step aside, even if she may choose to do so for a variety of reasons.

What is vital here is that, on Killmister’s account, dignity is not itself the kind of bottom out concepts in moral deliberation that we might expect. We can make reference to external reasons and standards in judging whether or not we have an obligation to make good on the demands of dignity. A norm “might conflict with the duty-bearer’s rights; it might clash with another of the duty-bearer’s obligations; it might be overly onerous; or it might be undermined by its own grounds, to name but a few” (Killmister 2020a, 82). This means that “we only have a moral claim not to have our dignity violated insofar as the obligations corresponding to such a claim are justifiable” (Killmister 2020a, 83). This is vital, among other reasons, because it allows us to distinguish between a reasonable request for communication and a
misogynistic demand of someone’s attention, and between the claims of a Black patient requesting a Black physician and a white patient requesting a white physician.

This points to a notable difference between Killmister’s account of dignity and the one I propose. For Killmister, these considerations of justice are external to the framework of dignity itself. As I show in the next chapter, the conceptualization of dignity that grounds dignity on my account has institutional and systemic considerations built in. It is part of Karen’s narrative that she was brought up in society barely coming out of explicit institutionalized segregation, and that this has profoundly influenced how she sees Black Americans. However, her perception of Black Americans as lesser-than does not accord with the facts, and this misinformation and bias is a definite part of her narrative that affects how we might approach this decision.

Let’s look at another case, one that concerns organ transplantation. Jacque and Monique both require a heart transplant. Their circumstances are strikingly similar. A heart has become available, and it will go to only one of them. It is unlikely that the other has sufficient time left to wait for another organ to become available. The only real difference in their circumstances is that Jacque has been on the transplant list for 2 weeks longer. Given the similarity in their cases, the transplant committee decided that the wait time is decisive, and that Jacque will get the heart. It is clear that both Jacque and Monique have very similar claims. It is also clear that the committee cannot make good on both claims, and that all things considered Jacque has a stronger claim. As Killmister suggests, passing over Monique should come with feelings of regret or sorrow. But ultimately no one was wronged by this decision.

**Killmister’s Tapestry of Dignity and Case Studies**

What would Killmister’s account mean for some of our core cases? Cases like *Capacity for Preferences* or *Amputation or Death* offer a valuable application of the dignity framework.

**Case—Capacity for Preferences**

[The patient is a] Forty-one-year old male who at age twenty-five had been involved in a car accident that left him paralyzed from the waist down and with a traumatic brain injury ... He had a court-appointed guardian and had lived in group homes since becoming paralyzed ... He was admitted to the hospital for stage 4 decubitus ulcers on his legs resulting from lack of hygiene and refusal of wound care ... the patient consistently refused wound care ... [and] denied that he was paralyzed. [Treating physicians were considering
three potential courses of action, namely] a six-week course of intravenous antibiotics [requiring] six weeks of prolonged restraint, amputation below the knee, or no curative action but comfort care in the hospital and then hospice once he became septic. (Wasserman and Navin 2018, 33, 32)

One of the key issues of Capacity for Preferences is that, since the patient is unrepresented, we lack substantive information about the personal norms of the patient, except that they refused wound care. However, a meta-analysis shows that the treatment of this patient risks the destruction of their status dignity, since the patient no longer holds the status as someone who participates in decision-making.

**Case—Amputation or Death**

The patient is a seventy-two-year old man without known friends or family, who suffers from hypertension, diabetes mellitus, peripheral vascular disease, and schizophrenia. He has been admitted with four necrotic toes. When he was previously admitted with a similar problem on his other foot, the physician and ethics committee jointly decided on a below-the-knee amputation (BKA). The patient consented on the condition that he would be provided a prosthetic leg. It was reasonably expected that he would be able to receive this. However, he was never fitted with a prosthetic leg, likely due to effects resulting from his mental illness. Given his current condition, preventing the spread of gangrene up the foot and leg would require amputation. The degree of damage cannot be determined pre-op, which means that amputation could range from removing just the toes, all the way to an above-the-knee amputation (AKA). Alternatively, the patient could be provided with a comfort-focused plan of care without amputation. This would likely result in sepsis and ultimately death. (UTMC Ethics Committee 2018)

In this case, it is clear that the patient values independence, and that taking away this independence would at the least constitute a frustration of personal dignity. However, it may also constitute a violation of personal dignity. This depends on how the patient perceives their post-amputation situation.

Finally, let’s look at an end-of-life case that does not involve an incapacitated patient.

**Case—(How) Do We Choose Our End?**

The patient is a 46 year old female patient. She came in “feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. They did a bone-marrow biopsy and
she was diagnosed with acute myelomonocytic leukemia. The oncologist proposed a course of induction chemotherapy, followed by consolidation chemotherapy, and finally a bone-marrow transplant. The survival rate of this course of treatment is about 25%. The survival rate of no treatment is about 0%. The oncologist met with the patient to inform her of the diagnosis and had made plans to begin induction chemotherapy that afternoon. This enraged the patient, who refused treatment. When the patient saw their treating physician several days later, they remained steadfast in their refusal for treatment, with limited support from their family. A couple of weeks later, the patient came to the physician requesting barbiturates to aid in sleep. While barbiturates can be a powerful sleep aid, their non-prescription use can also result in death. In conversation with the patient it becomes clear that they are planning to use it as a sleep aid, but that they are also aware of its secondary use, and wish to have enough of the medication to be able to commit suicide. By law, the physician is banned from providing assistance in patient suicide. The physician must choose whether or not to assist the patient. (Originally from Quill 1991a)

The patient may well be afraid of the destruction of their personal and social dignity. That is, a worry that an end of life that is outside of their control will be a slow decline into a state in which they are unable to hold themselves to personal and social norms. Deciding their own death may well be ennobling, and an opportunity to reinforce self-respect. It is not clear on this account whether the patient has a claim on the prescribing physician.

**Critical Discussion**

There are three primary differences between Killmister’s approach to dignity and my own. One of these is conceptual, and the other two concern scope. First, Killmister understands dignity as a property that is conferred either through the possession of personal or social norms, or in virtue of membership in some relevant category. That is, to have the relevant norms or status is to have dignity, and this dignity can subsequently be respected or damaged. While I interpret Killmister’s account as relational, she does not use this terminology to refer to her own view. It nevertheless shares important characteristics in common with other relational views. For one, Killmister rejects the metaphysical understanding of dignity. Secondly, a significant portion of Killmister’s account concerns respectful treatment, which is about “the relationships between people,” and can be “conferred in social relations” (Killmister 2020a, 12, referencing Rosen 2012, 6; quoting Barclay 2018, 4). This is different from my understanding of dignity as realized through interpersonal decision-making and
action. As the next chapter will demonstrate, dignity is realized in the appropriate response to one's narrative.

Second, Killmister’s view is broader than mine in terms of its theoretical breadth. Her aim is to offer a comprehensive account of dignity that accounts for the great diversity of moral work the term does. This is by her own admission not meant to be definitive; rather, she hopes “to develop a theory of dignity that is useful, insofar as it resonates with, and helps us reflect upon, our moral lives” (Killmister 2020a, 3). I echo this in a more restricted sense. While I take my view to be relevant to applied ethics more broadly, and perhaps normative ethics in general, this project is focussed on dignity in the context of clinical ethics.

Third, Killmister’s view is narrower than mine in what it recognizes as the grounds of dignity. Killmister’s conceptualization of dignity is grounded in the norms we set for ourselves, that our society sets for us, or that are attached to the relevant status(es) we enjoy. It’s not exactly clear which part of the individual are norm-generating. Values, for instance, are clearly normative. But this is less obvious, for instance, for features like desires and relationships. The account I propose more clearly delineates the relevant normative components through the conceptualization of narrative as the set of relevant norm-geneting features. Moreover, because narrative consists in a very broad set of features, the account has significant extensional capacities. Killmister’s view is able to account for human rights through the social kind of human being. This is a somewhat malleable category that may (come to) include certain other beings, such as great apes and humanoid extraterrestrials. However, this malleability moves both ways, and it also risks excluding certain categories of people. Human rights stands and falls with being recognized as a proper member of the category human being. I am not here interested in human rights as such, though I think there is room to accommodate a lot of what we find valuable about human rights discourse in terms of our institutional relationships and commitments.

On my view, the grounds for dignity is narrative, which is a very accommodating category. In the terms Killmister and Darwall use, possessing a narrative requires recognition respect. That is, all beings with a narrative must be accorded the recognition respect that acknowledges this narrative. The content of the narrative is then the subject of appraisal respect. However, the features of narrative are quite expansive, and as a result we can speak meaningfully of narrative, and by extension of dignity, in a broad variety of cases. This includes not merely incapacitated human beings, but also animals, the environment, and even the (recently) deceased.  

---

25 I elaborate on the extensionist potential of my view toward the end of the next chapter.
C. Linda Barclay’s Relational Dignity in Health Care

In her article “In Sickness and in Dignity” (2016), Linda Barclay makes a claim that echoes throughout the preceding sections of this project, namely that “Much of what philosophers have historically said about dignity is abstract and extremely difficult to apply to the concrete setting of health care” (Barclay 2016, 137). Nevertheless, Barclay resists the Schopenhauerian inclination to kick the concept to the curb. Instead, in “Dignitarian Medical Ethics” (2018), she offers an account of dignity that is focused specifically on the context of healthcare. Barclay’s view is of interest, because it draws on and challenges Killmister’s account in order to propose a view of dignity that is especially relevant to health care. It also borrows heavily from Killmister, and both cite Luban as an influence. Killmister and Luban both identify dignity with non-humiliation, but this is a move that Barclay resists (Barclay 2016, 137). Barclay categorizes her view as a status dignity account, primarily because she understands dignity as something that is conferred (Barclay 2018, 63). Instead, she claims that “Although of great importance, I do not believe that avoidance of humiliation and reduced agency exhaust the reasons we have for treating people as social equals” (Barclay 2018, 65). To support this claim, Barclay offers an analysis of the social meaning of dignity-related concepts, and the ways in which these can undermine the core aims of various accounts of dignity.

Barclay cites Sally Haslanger’s development of the concept of “schemas,” which are “culturally shared concepts, beliefs and other attitudes that enable us to interpret and organize information and coordinate action, thought and affect” (Barclay 2018, 66, quoting Haslanger 2016, 126). These schemas are vital to our social functioning, but they can operate in insidious ways. Their ubiquity and self-fulfilling, recurrent nature can easily create the illusions of naturalness, especially over time. That is, “we respond to the world that has been shaped to trigger those very responses without being conscious of the shaping, so our responses seem to be called for by the way the world is’” (Barclay 2018, 66, quoting Haslanger 2012, 468). For instance, a fiscal conservative bootstrap-ideologue believes that poor people are lazy. When someone comes from a poor background and lacks the opportunities to succeed, they see this as confirmation of their view that the poor are poor by choice. Poverty is just a natural consequence of laziness. And because their view is confirmed by the evidence before them, they need not question it. Barclay explains that “The core idea is that the way we treat one another in our daily exchanges both arises from, but also reinforces, social meanings that can facilitate mistreatment. Treating people as social inferiors has social meaning of this nature” (Barclay 2018, 66).

Through the use of schemas, Barclay demonstrates that the limits of dignity is not just a matter of abstract theoretical concern. Theoretical limits can affect our
socio-cultural practices to such a degree that what comes as the results of such practices appears as natural fact. For instance, consider a patient with diminished agency who is being treated as less than equal. We might look at this situation through the lens of dignity and conclude that this treatment is a response to a lack of (or diminished) dignity in the patient. If we look at this situation through the lens of schemas instead, then we can see that the actions are informed by social standards that give the appearance of the absence of dignity, wherefore the actions are inappropriately signaling the lack of (or diminished) social status.

Barclay guards against the identification of dignity with nonhumiliation, because she sees nonhumiliation as being “at odds with the robust capacity for effective agency” (Barclay 2018, 65). This seems to entail that in the absence of this robust capacity for effective agency, there is no disrespect and humiliation. This is precisely Barclay’s concern, when she suggests that “it would follow [from dignity as non-humiliation] that we have no reason to treat people with severe dementia, or other forms of severe cognitive impairment, with dignity,” and this follows precisely because “Many such individuals are not capable of feelings of humiliation, nor of independent agency” (Barclay 2018, 65). Barclay suggests that in order to understand the need for an accurate and inclusive account of dignity “We need to look at what further harms relations of social inequality can inflict” (Barclay 2018, 65). Based on her discussion of schemas, she recognizes that “The failure to treat people with cognitive impairments as our social equals in our everyday exchanges is part of a wider pattern of cultural, political and legal maltreatment. It is harmful in ways that go beyond its contribution to humiliation and reduced agency” (Barclay 2018, 66). Barclay demonstrates the broader, social harms that come out of a failure to recognize the role of dignity in health care. The harm here is that this failure over time comes to be seen as the appropriate response to an actual lack of dignity.

So how can we resist this insidious schema? Rather than focus on narrative (Luban), or personal and social norms (Killmister) as the grounds for dignity, according to Barclay “dignity is conferred in social relationships where we follow social norms for treating people as sharing equal status” (Barclay 2018, 63). In the context of healthcare, this certainly includes cases where the patient “is able to live in accordance with his or her standards and values” (Barclay 2016, 137). But this is important precisely because “It signals that each and every one of us is equally worthy” (Barclay 2016, 141). It’s this socially conveyed notion of equality that Barclay argues is central to dignity. On this view, dignity conferred onto a person through their being treated as an equal by another, which makes the view relational. And despite important differences between the accounts of Luban, Killmister, and Barclay, there are clear elements shared in common. One is the centrality of relationships to dignity, the conception of humiliation as violations of dignity, and understanding autonomy as the “closely entwined” notion of exercise of “control and choice” (Barclay 2016, 140, citing Killmister 2010, n.p.).
In part based on these similarities, Barclay concludes that “the concept of dignity is considerably less ‘deconstructed’ than much of the existing health care literature would indicate” (Barclay 2016, 137). While this may be true, the problem with the assessment is that it relies on identifying dignity with its broadest category. Dignity as the proper recognition of a person’s status is a feature of most and consistent with all of the accounts of dignity. While Barclay’s account demonstrates the ways in which her view, as well as those of Luban, Killmister, and myself, are ultimately status dignity accounts, the emphasis on status ultimately means that the account remains general. Barclay recognizes that “There are many factors that patients identify as threatening their dignity” and concludes that “Most of them are best understood as behaviors that treat them as though they are of lower social status” (Barclay 2018, 66). While we can certainly make sense of dignity undermining treatment as actions that communicate to the patient that they are of lower social status, this fails to provide content to what equal social status requires, especially in the case where someone’s capacities are undermined. This is not to say that limited capacities entail limited social equality, but it does mean that one cannot assert their equality in the usual way, for instance through autonomous decision-making.

Barclay’s view offers a valuable analysis of the relationship between the need for surrogate decision-making and how this unjustly contributes to our social understanding of incapacitated patients as lesser-than. It also bolsters the claim to resist this kind of insidious schema, and work to acknowledge and treat incapacitated patients as social equals. What this entails exactly is left open, no doubt in part because the article is relatively brief, but also because what social equality means and demands can vary depending on the context. My view coheres with Barclay’s account, insofar as it works out what social equality means in terms of dignifying another person, in particular in a medical context.
Chapter 3: Narrative-Based Relational Dignity

A. A New Kind of Relational Dignity

I am proposing a different view of dignity, one that has not yet been argued for. On this account, dignity is not a kernel of value, or a basic status of moral considerability. The narrative-based account of relational dignity locates dignity in the interaction between persons. This makes dignity a lot less like status than on most other accounts of dignity. And among the relational views discussed in the previous chapter, this is the most explicitly relational view. This is because, rather than considering dignity as a noun referring to a property in or of people, it conceives of dignity as a transitive verb, like understanding or listening. So the question is not about whether we have dignity and what this means, but how we can dignity others in our actions and decisions. The narrative-based relational view of dignity holds that (1) every person has a narrative that is comprised of the features that together constitute the structure of a person’s life, and; (2) that dignity is realized when someone’s narrative is responded to appropriately in actions or decision-making that affect this person. Dignity on this account is relational in a very literal sense. It is transitive, like being understood, and to be understood requires an interlocutor that understands. In order to be dignified, our narrative doesn’t merely require expression or utterance, it requires uptake. While it is a relatively straightforward expression of the social relationship that is required for dignity, this is by no means easy. Narrative, as we’ll see, is not just testimony, but constitutes a set of features that each contribute to the structure of a person’s life.

In this chapter, I first develop the relevant notion of narrative, as this provides the grounds for narrative-based relational dignity. This includes contrasting “narrative” with related terms, setting out the constitutive categories and features of narrative, and motivating this conceptualization of narrative through a discussion of its status as metaphor and its relation to literary theory. Second, I use this account of narrative to return to the sketch of the dignity offered above, and develop the narrative-based relational account of dignity in greater detail in positive terms. This also involves a concrete contrast with the other relational accounts, in particular those of Luban and Killmister. In addition, I discuss the need to resist specifying necessary and sufficient conditions for dignity, and how this account meets the desiderata set out by Killmister, which were discussed in chapter 2. Third, the narrative-based account of dignity is applied to a series of cases. This highlights its strengths and contrasts with alternative conceptions of dignity. Finally, I discuss the possibility of an extensional account of dignity. That is, I evaluate the limits, or lack thereof, of the narrative-based account, and what this means for the possibility of dignity outside of living human beings.
B. The Nature of Narrative

Many areas of thought, including philosophy and medicine, are moving to alternative conceptualizations of the self, ones that are more narrative and relational. Examples of this are found in deep ecology, biocentrism, narrative theories of personal identity, and care ethics. Despite their relative novelty in the West, views like this have enjoyed millennia of popularity in other regions of the world. They promote the idea that at its foundation humanity involves a great variety of capacities and our being connected to one another and our environment.

Narrative, Story, and Testimony

There are different ways to understand the narrative-related language. The terminology in this context is diverse, but I focus on three key terms, namely “narrative,” “story,” and “testimony.” “Narrative” is sometimes understood as equivalent to “story,” and Luban on occasion uses “narrative” and “story” interchangeably, so it’s clear that he has this kind of thing in mind. However, the connection between “narrative”/“story” and “testimony” is not immediately clear, especially considering the judicial context. Luban sees it as part of a lawyer’s job to hear and interpret their story, so they can present it to the court as an official testimony. Here, “testimony” is a technical legal term. But what the lawyer, acting as an advocate, requires for this to be possible, is the individual’s testimony, broadly construed. Here, “testimony” just means what the individual verbalizes about their story or experience. There are a variety of legitimate uses of these terms; however, in the context of the view that I propose, I want to avoid confusion by ensuring that these terms have a particular meaning. I understand these terms as follows:

**Story.** Someone’s life story is the entirety of the events and relationships that have happened during their life. It is their history, as a matter of fact, and uninterpreted.

**Narrative.** The structure of a person’s life. Their full and comprehensive background. The entire arc of their history. The tapestry of their lived experience. In particular, as this is relevant in the current moment.

**Testimony.** This is what a person says about their situation or narrative. This is one of the expressed elements of narrative.

What distinguishes “story” and “narrative” as I’m using the terms here? “Story” is the more comprehensive term, as it contains everything about the person’s life. This will inevitably contain a lot of irrelevant data. For instance, what I ate for dinner the night
before my fifth birthday is part of my story, but it’s not relevant to anything that’s happening today. “Narrative,” therefore, is the more focussed term. It draws out of one’s story the relevant elements. As we’ll see, in cases of surrogate decision-making, it is the surrogate’s responsibility to take up with the arc of the person’s life up to that moment, the situation that is before them now, and engage in decision-making that continues to weave the tapestry of their lives in a coherent, and thus dignifying, way.

In order to clarify the difference between narrative and testimony, consider the following case.

\[ \text{Case—Going Home to Dolly} \]

Mary Beth is a 68 year old female patient who was hospitalized after a fall in her own home. She was down for at least a full day before EMTs found her after a call by a concerned neighbor. After several days in the hospital Mary Beth is making a decent recovery, but it’s not clear that she can live on her own. She has limited mobility, is at a high risk of falling and injury, and she is showing early signs of dementia. When asked what her plans are after discharge, she explains that she’ll go back home. When asked about help inside the home, she explains that she knows Dolly Parton quite well, and Dolly will be checking in on her regularly. It is clear from extended conversations and evaluation that she is saying this in earnest. After checking with neighbors, it is clear that Mary Beth has no personal relationship with the country music icon, and that she is confabulating about her post-discharge situation.

One way of responding to this situation, is to say: “Look, clearly Dolly Parton is not going to be making any visits to Mary Beth’s home. But this is the story she’s telling us and herself. This is her narrative, and since our narrative approach to clinical ethics demands that we respect this story, we ought to discharge Mary Beth based on her stated plans.” In this case, the hospital staff would not be responding to Mary Beth’s full narrative, but rather to her testimony. Here, testimony is someone’s personal expression of what they understand to be their story or situation. Testimony is incredibly valuable, because it provides the best opportunity to get directly at the person’s perspective. However, testimony can also be affected by pathology, influenced by a misapprehension of relevant facts, or a person’s attempt to paint the situation differently. And in some cases, for instance when someone is unconscious or delirious, there is no opportunity to obtain testimony at all.

I take “narrative,” “story,” and “testimony” to refer to related but distinct phenomena. Testimony is a self-report, i.e. what a person says about themselves and their situation. A person’s story is the totality of the facts about them. This includes their testimony as well as facts about themselves that are not self-reported. Narrative
is an account or recounting of their story relativized to a particular context. This is a broad understanding of narrative, and one that borrows quite heavily from literary theory. This notion of narrative includes testimony and other facts about the person, such as their actions, preferences, and values, as well as their relationships. It also includes relevant facts about the society in which they live, and the structures and institutions to which they are subject.

One important distinction between narrative and testimony, is that the former is responsive to facts about the world. So while a response grounded in testimony would see Mary Beth discharged, considerations based on narrative would be much broader. Mary Beth’s discharge plan relies on her relationships with Dolly Parton, who should be checking in on her regularly. However, we have found no evidence of such a relationship, so it seems that if Mary Beth is discharged to her home, she will be on her own. Her current state suggests that this is not a stable situation in the long term, and so we should consider alternatives. We should discuss this with Mary Beth, perhaps by informing her that we don’t think Dolly will have time to visit her a lot, and so we need to make other accommodations. At this time, without further planning, discharge is unwarranted. In other words, the narrative approach does include Mary Beth’s testimony about her plans, but it also includes the actual facts of her health and situation. This is vital, because testimony can be incomplete, dishonest, or affected by pathology. Narrative therefore does include testimony, but also goes beyond that by including a broader array of features.

Elements of Narrative

Narrative is a composite notion that is constituted by four categories, each of which consists in multiple features or elements. The first category concerns the expressed elements of narrative. Testimony is one of the features in this category, and as an element that is generally conveyed through verbalization, it is a prime example of an expression of narrative. Other external expressions of narrative include behaviors and actions. Embodiment is also part of this category, insofar as we think of this as concerning our physical being in the world. The second category is personal elements of narrative. This concerns “internal” features of our narrative, such as attitudes, desires, and phenomenology—our direct first person experience of ourselves and our body in the world. This is a vital aspect of our narrative, especially in medicine. This also includes facts about our history, both personal and medical. The third category concerns social elements of narrative. This is meant to capture our relationships, broadly construed. I.e. our relationships with family, friends, acquaintances, but also to work and the various communities we enjoy membership in. Finally, the fourth category are the structural elements of narrative. This is a very broad class of features, and includes the various structures and institutions that they are subject to, both local and global. This includes a person’s demographic.
designations, such as race, sex, gender, and class, along with the cultural meaning that these entail. In addition, this category extends to the relevant laws and policies. This includes municipal, state, and federal law, as well as organizational policies. In a medical context, this certainly includes various hospital regulations, as well as relevant policies by professional organizations such as the AMA. This can also include religious doctrine and cultural standards.

In order to further shed light on this notion of narrative, I have set out the aforementioned features along with others, specified according to the four categories of narrative, below. A person’s narrative includes at least the following non-exhaustive lists of elements:

<table>
<thead>
<tr>
<th>Expressed Elements of Narrative</th>
<th>Personal Elements of Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Testimony</td>
<td>● Attitudes</td>
</tr>
<tr>
<td>● Behaviors</td>
<td>● Desires</td>
</tr>
<tr>
<td>● Actions</td>
<td>● Values</td>
</tr>
<tr>
<td>● Embodiment</td>
<td>● Preferences</td>
</tr>
<tr>
<td></td>
<td>● Understanding</td>
</tr>
<tr>
<td></td>
<td>● Phenomenology</td>
</tr>
<tr>
<td></td>
<td>● (Medical) History</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social Elements of Narrative</th>
<th>Structural Elements of Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Relationships to Family</td>
<td>● Institutions</td>
</tr>
<tr>
<td>● Relationships to Friends</td>
<td>● Laws</td>
</tr>
<tr>
<td>● Relationships to Church</td>
<td>● Policies</td>
</tr>
<tr>
<td>● Relationships to Work</td>
<td>● Cultural Standards</td>
</tr>
<tr>
<td>● Relationships to Local</td>
<td>● Demographics</td>
</tr>
<tr>
<td>Communities</td>
<td>(race/class/sex/gender)</td>
</tr>
</tbody>
</table>

These categories are meant to provide structure to the discussion of narrative. They are, as such, *ad hoc* and superimposed. There is obvious variability in how we may categorize these, and I do not suggest that a person's narrative cleanly breaks up into all of these distinct categories or discrete elements. Narratives are as variable as people are, and these elements and their interrelations will look differently for each person. Embodiment also concerns “internal” lived experience, and as such is a personal element. Attitudes and values are, almost by definition, parts of ourselves that inform how we behave and act, and so are part of our expressions and inform our relationships. Social and structural elements often run into one another, though social features are meant to point at closer, personal relationships and structural
features at more abstract ones. In order to further elucidate this concept, let's analyze a case in terms of narrative.

Case—(How) Do We Choose Our End?

The patient is a 46 year old female patient. She came in “feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. They did a bone-marrow biopsy and she was diagnosed with acute myelomonocytic leukemia. The oncologist proposed a course of induction chemotherapy, followed by consolidation chemotherapy, and finally a bone-marrow transplant. The survival rate of this course of treatment is about 25%. The survival rate of no treatment is about 0%. The oncologist met with the patient to inform her of the diagnosis and had made plans to begin induction chemotherapy that afternoon. This enraged the patient, who refused treatment. When the patient saw their treating physician several days later, they remained steadfast in their refusal for treatment, with limited support from their family. A couple of weeks later, the patient came to the physician requesting barbiturates to aid in sleep. While barbiturates can be a powerful sleep aid, their non-prescription use can also result in death. In conversation with the patient is becomes clear that they are planning to use it as a sleep aid, but that they are also aware of its secondary use, and wish to have enough of the medication to be able to commit suicide. By law, the physician is banned from providing assistance in patient suicide. The physician must choose whether or not to assist the patient. (Originally from Quill 1991a)

Given the provided details of the case, what can we reasonably conclude about this patient’s narrative? In response to this question, I offer a brief breakdown of the case in terms of narrative by category. Not all features of each category are represented, as will often be the case either due to limited information or lack of applicability. Nevertheless, this and similar evaluations in subsequent sections should make clear the kind of analysis of which this framework is capable, and the ways it can be expanded when presented with new information.

Expressed Elements of Narrative

- **Testimony:** The patient has expressed that they are not interested in treatment for their cancer. They indicate a desire for palliative care in the form of sleep aids, as well as the availability of sufficient drugs to facilitate suicide.
- **Behaviors:** The patient is experiencing trouble sleeping.
- **Actions:** The patient is actively researching their options.
Personal Elements of Narrative

- **Attitudes**: The patient has disapprobative attitudes toward the oncologist recommended treatment plan.
- **Desires**: The patient desires a comfortable end of life with control over the time and place of her death.
- **Values**: The patient's values appear consistent with the relevant desires.
- **Preferences**: The patient prefers a self-regulated death over the natural progression of their disease.

Social Elements of Narrative

- **Patient's relationship to their family appears good, and they enjoy the support of their family in rejecting treatment.**

Structural Elements of Narrative

- **There are many structural issues that relate to this case, but most importantly are the professional and legislative constraints that exist in this context. The AMA generally disapproves of physician assisted suicide, and the time and place in which this case is situated entails that there are legal prohibitions against physician assisted dying as well. While these could perhaps be circumvented in the case of a willing physician, if the patient finds themselves admitted to the hospital, active euthanasia will almost certainly not be an option for them.**

At this point, I am not yet providing an analysis of dignity, and so I do not attempt to resolve this case. However, it is clear that a narrative analysis is able to lift out several important aspects of this situation by highlighting key expressed, personal, social, and structural features. Taken together, this sketches a coherent narrative of a person that understands their situation, the options that may and may not be available to them, and has clear intentions for their decisions and actions moving forward.

**Narrative and Literary Theory**

A person's narrative is the structure of a person's life, in particular as it is relevant in their current moment. This is different from their story, which is their full and interpreted history, as well as testimony, which is what they verbally express about their narrative. There are different ways in which we can understand the social relationships involved in grasping someone’s narrative. One important point to recognize here is that, much like the notion of story in Luban’s discussion, “narrative” is a metaphorical term. It is meant to evoke a certain kind of characteristic, a particular way of approaching a person and their life. In terms of the relation
between narrative and literature, I first discuss the connection to literary criticism, in particular structuralism. And secondly, I develop the connection to hermeneutics.

The status of narrative as metaphor does not mean it’s ill suited to the job I’m outlining for it here. Rather, there is significant strength in the connections its analogousness entails. For one, to drive the analogy with literary narrative home, we can borrow some language from literary theory. To conflate narrative with testimony, is to insist on a model of authorial intentionalism, where the author of the narrative is understood to be the authority concerning the meaning of the text. If Melville says that there is no allegory in his *Moby Dick*—"So ignorant are most landsmen of some of the plainest and most palpable wonders of the world, that without some hints touching the plain facts, historical and otherwise, of the fishery, they might scout at *Moby Dick* as a monstrous fable, or still worse and more detestable, a hideous and intolerable allegory" (Melville 2018/1851, 164)—then there is no allegory, and “the white whale" stands for nothing but the linguistic representation of the *physeter macrocephalus*. A century of literary criticism has to swallow its words about the Great American Novel. And similarly, in *Going Home to Dolly*, when Mary Beth claims that she and Dolly Parton are close friends, we must set aside all evidence to the contrary and accept her claim as true. Yet, we tend to take serious interpretations of Melville’s novel that he himself would have rejected—and did in fact reject. And we tend to take serious the kinds of evidence that suggests Mary Beth and Dolly are not close friends. Movements in literary theory at least since new criticism have rejected the author’s absolute authority entailed by authorial intentionalism as a fallacy in interpretation.

New criticism transplanted the authority of meaning wholly from the author to the text itself. That is, we should interpret the text as an independent object, without any reference to the author and their situation. On this view, neither Melville nor Mary Beth’s testimonial expressions carry any (direct) weight. This school of thought effectively denies the artist their unique relationship to their work after creation. The text becomes a circumscribed object of its own, divorced from its author, with all relevant, objective meaning contained within it. This model has been criticized for its understanding of the text as unaffected and unattached.

Subsequent schools of thought have focused on relational features of the text. Structuralism tells us that the effect of structures and institutions on the text is fundamental and inextricable. We cannot reasonably separate the story from its cultural and historical context, both in which it is created and in which it is interpreted. This conceptualization of narrative proposed here derives in part from the structuralist tradition, and holds that this same kind of relationality is true for the individual. For one, while narrative includes testimony and other facts about the person, it also includes relevant facts about the society in which they live, and the structures and institutions to which they are subject. This means that narrative is able to move far beyond mere testimony, and is able to respond to the individual’s
social circumstances and account for facts about the world. We can confidently say that, in *Going Home to Dolly*, Mary Beth does not have the kind of relationship to Dolly that she contends as part of her discharge plan. Moreover, other facts about her social situation may also be relevant to discharge, including the availability of beds in care facilities and whether or not her insurance will cover such a transfer.

Literary theory in no way culminates in structuralism, and we might see this as evidence that our view of narrative, supported by structuralism, is itself dated, insufficient, or incomplete. This conclusion would be unwarranted. Structuralism has primarily been superseded by frameworks that attempt to show the ultimate interobjectivity of language: language is a construct, and because it is not objective, concepts will ultimately contradict themselves. This kind of post-structuralism and deconstructivism are nihilists about Truth and Meaning, or at the very least about the ability of language to convey them. Whatever our ultimate judgment about these views and their theoretical and analytical prowess, they are of little use in cases where the need to convey is fundamental. Structuralism, by contrast, produces an understanding of narrative wherein the author is *central*, even though they are themselves not the *exclusive* authority on the nature and meaning of the narrative. In the context of clinical ethics, this lack of exclusive authority immediately evokes rampant paternalism—but it needn’t. We can see why by fleshing out the relational nature of narrative interpretation through the related field of hermeneutics, for instance by looking at the work of Hans-Georg Gadamer.

In *Truth and Method* (2006/1975), Gadamer posits that truth and meaning are not objective features of the author’s intent or the text or the reader’s interpretation, but come about as the relationship between these. Hermeneutics is about interpretation, and it recognizes the relational nature of narrative. Gadamer explains that “Total mediation means that the medium as such is superseded (aufhebt),” noting that “the work presents itself through … and in [the performance of the work]” (Gadamer 2006, 118). The nature of the work, including the process of its creation, are present in encountering the work. Yet at the same time, we need not “abstract from the work's relations to the life world in order to grasp the work itself. Rather, it exists within them. (Gadamer 2006, 119). Truth and meaning are therefore fundamentally relational.

When we experience a work of art, say a novel, the process of interpretation is a mediation. We have to take what the author presents to us in this particular form, and experience it by viewing it through our own lens, filtered by our own experiences and values and so on. And so we have to engage in this process of engaging with the work and adjusting our perception of it, until we reach a point of understanding of the meaning of the work. Theodore George, in “Hermeneutics” (2020), explains that for Gadamer, to reach understanding is to “recognize something that purports or claims to be true” (George 2020, n.p.). So there are three elements to interpretation: the producer of the narrative, the narrative, and the perceiver of the narrative. Why
does this matter? Gadamer shows us that narrative interpretation is an inherently imperfect process. And the less of the narrative we’re presented with, the harder it will be to tie it back to the person the narrative belongs to. However, if we do the work, we can come closer and closer to understanding—to truth. As George explains:

> There is, as anyone who has experienced an artwork will confirm, no method to ensure the success of this process of repeated projection and supersession; it depends on the quality of our interpretive work, and, this quality can be enlarged by our formation of our capacities such as common sense, judgment, and taste. (George 2020, n.p.)

Imperfect doesn’t mean hopeless, and there are better or worse ways of being imperfect.

There is a fairly straightforward isomorphism between the author-text-reader triadic-relationship, and that between patient-narrative-clinician. The lesson of hermeneutics is that truth comes out of this relationship. Moreover, hermeneutics demonstrates the limits of objectivity. And any framework for surrogate decision-making must include an acknowledgement of the mediation that this involves. This might prima facie seem like a significant loss, insofar as process entails a distancing or removal from the individual. But this is not quite right. As Gadamer explains with respect to interpretation:

> A person who learns to understand a text in a foreign language will make explicitly conscious the grammatical rules and literary forms which the author followed without noticing, because he lived in the language and in its means of artistic expression. … We must remember this especially in regard to the interpretation of poetry. There too it is necessary to understand a poet better than he understood himself, for he did not “understand himself” at all when the structure of his text took shape within him. (Gadamer 2006/1975, 191).

One of the jobs of the clinical ethicist is to help interpret people’s narrative in a way that may even exceed their own understanding. In order to clarify what this might mean, consider the following case.

**Case—Home Is Where My Car Is**

The patient is a 58 year old male, who presented with a variety of health issues, including renal disease. In trying to obtain a medical history, the patient frequently seems confused and appears to be confabulating. A psychological evaluation determines that the patient is likely suffering from early-stage dementia. Throughout their time at the hospital, they are eager and adamant
about returning home. However, their situation requires a stay at a short-term care facility, and the dementia may eventually require a permanent move. The patient is concerned about spending any extended amount of time away from home, and refused any such short-term or long-term placement. The patient’s refusal of placement raises a difficulty for their current treatment and discharge plan, and is likely to cause further complications in the future. Recognizing this, one of the clinical ethicists meets with the patient. In conversation, it turns out that the patient owns the house. They were able to buy it nearly twenty years ago, after a series of misfortunes and a string of homelessness. To them, the house represented financial and physical freedom and independence. And without an heir or anyone in their life to assume responsibility for the house and their financial affairs, the patient was unsure what would happen to the house. This caused them to become recalcitrant with respect to any option that involved extended out-of-home care.

For this patient, the attitudes concerning their home were present, but implicit. It is in dialogue with clinicians that this part of their narrative is able to breach the surface. This knowledge of course does not resolve the immediate situation the patient has found themselves in, but the understanding this creates does allow all parties to move forward in a way that is better able to dignify the patient.

Given the significant work the third party has to do toward understanding the text or the patient, there is a serious concern about projection. That is, given people’s general disposition toward interpretation according to their own frame of reference, it seems that this process poses a significant risk of overriding the patient’s narrative with our own. Gadamer recognizes this as well, and responds as follows.

A person who is trying to understand a text is always projecting. He projects a meaning for the text as a whole as soon as some initial meaning emerges in the text. Again, the initial meaning emerges only because he is reading the text with particular expectations in regard to a certain meaning. Working out this fore-projection, which is constantly revised in terms of what emerges as he penetrates into the meaning, is understanding what is there. (Gadamer 2006, 269).

These warnings—about the limits of objectivity, the relationality of truth and meaning, and guarding against projecting—are all internal to the framework. They are part and parcel to what proper takeup with a person’s narrative means.

One implication of the understanding of narrative developed here, is that it entails that we are able to read different narrative-threads into the elements that are constitutive of the patient's narrative. This fits with our hermeneutic analysis as well, as this is analogous to how we might read a book. Two people can read the exact
same book and come away telling different versions of that story. And neither version may technically be wrong, it’s just that people pick up on different pieces of the story and interpret them differently. Importantly, we need not conclude that either interpretation is false, or that the text itself is deeply flawed, conflicted, or in some way invalid. It certainly may be the case that a textual interpretation is false—for instance, interpreting books that critically discuss issues of racial disparity as being racist in light of the discussion itself is a misinterpretation. However, literary characters, like real life people, are often bathed in ambiguity. We can give more or less generous interpretations of their character, their actions, behaviors, and history. We can legitimately come away with different, valid understandings of the text and its characters.

The same is true for interpreting people’s narratives. There is a sphere within which different people can interpret the elements of narrative in coherent and reasonable ways. Here, too, we must not conclude that narrative interpretation and proper uptake are bunk or an exercise in futility. Rather, as with textual interpretation, these complications emphasize the responsibilities that are entailed by narrative engagement. A clinician that is working to understand a patient’s narrative is indeed working to understand it; to take up with the narrative properly. This entails significant demands of time, empathy, compassions, and more.

There are two important points to emphasize with respect to the multiplicity of narrative, namely the competing forces of variability and constraint. First, the possibility of competing interpretations is constrained both by the requirement for the interpretation to be plausible and reasonable, and the fact that there can be better and worse ones. Moreover, variability in interpretation does not necessarily entail a complication in surrogate decision-making, as differences may not be relevant to the particular decision or set of decisions. In the case that equally possible but conflicting interpretations do arise, an effective protocol for surrogates will include a method for prioritizing one interpretation over another or others. Developing this method is part of the future of this project, as I take the issue of the proper ordering of competing narratives to primarily be an applied question.

Second, the variability of narrative highlights the adaptability of the framework in light of the complexities of narrative. One way of expressing different schools of thought in literary theory is through critical lenses. We can metaphorically don our Marxists reading glasses and read a text in terms of class analysis, or we can put on our LGBTQIA+ glasses to offer a queer analysis, and so on. Similarly, we can interpret narratives—even our own—through various lenses. When I’m deciding whether or not to accept a job offer, I may put on my professional glasses, and when I’m deciding whether or not to move forward with a medical treatment, I’m wearing my health care glasses. While my story and I are still at the center of each version of the resulting narratives, the results will nevertheless look very different. This is to say
nothing of how radically different the narratives and ultimate decisions may look for different people, even if their situations are on the surface incredibly similar.

What we often find in ethical theory, and in particular in more universal views, is the requirement that the theory produces very similar recommendations for action in response to very similar circumstances. Otherwise, the worry is that the view is arbitrary. However, the variability in recommendations to seemingly similar circumstances is a feature, not a bug, of the view under consideration here. This is precisely because the view rejects that “basic” facts are sufficiently representative of a situation. This would be akin to describing literature in terms of its tropes.

Moreover, we can see that Kantian ethics strives for perfect answers. All actions and decisions are based on hypothetical rules of action that can be universalized so as to check its status against the a priori—the universal and the good. Even in one of the primary competing views, utilitarianism, we can see the striving for perfect answers. If we get the math just right, we can know what action will produce the very best consequences.

The narrative-based framework does not purport to work toward perfection. Human beings as such are complicated and often conflicted, and recognizing the potential discord and indeterminacy in our narratives is not to set us up for failure, but to reckon with a fundamental feature of our humanity. On more traditional models of successful surrogate decision-making, i.e. ones that reflect the universal account of dignity, successful decision-making is understood as reflecting abstract principles and a respect for fundamental human value. This results in greater conformity across situations. Relative to these traditional views, the framework proposed here introduces more opportunities for uncertainty, indeterminacy, and error. These are not criticisms of the view—as they might be for more universal views—but an authentic reflection of the phenomena of surrogate decision-making.

One might wonder why, given its centrality in our discussion and its status in ethics more generally, dignity is not itself the bottom out concept. In explaining dignity in terms of narrative, are we not just trading in one mysterious concept for another? This is a prima facie legitimate concern. Dignity is a malleable concept that has been used to cover for moral intuitions, and to attempt to give content to dignity by grounding it in an equally vague or undefined concept would only serve to push the problem off an extra step, without ultimately resolving anything. However, this is not a problem for this account. Insofar as we are disposed to think about dignity as a property in persons, this narrative-based relational dignity is decidedly revisionist. It has none of the mystery that metaphysical accounts entail, as it identifies dignity as the proper uptake with someone’s narrative. Had narrative itself been a squishy concept, then we would be back at square one. Fortunately, this is not the case. While the content of narrative is flexible and adaptable, the nature of narrative as such is fixed. Capturing the structure of a person’s life in terms of narrative is, of course, a metaphor. But it’s not mere metaphor, because analogizing these features
of a person's life to a literary category actually does theoretical work. Looking at literary criticism allows us to develop a better sense about what the structure of someone's life entails. It also allows us to think about the relation between the person, their narrative, and the individual who is acting or deciding in a way that affects the person. Gadamer understood this as well, as he fittingly notes:

Like the coherence of a text, the structural coherence of life is defined as a relation between the whole and the parts. Every part expresses something of the whole of life—i.e., has significance for the whole—just as its own significance is determined by the whole. (Gadamer 2006/1975, 218-9).

The way the author expresses themselves in their text is affected by their circumstances. The text represents their intent as well as their possibilities and limitations. The reader who encounters the work brings with them and to it their own situation. Just as there is no perfect representation of the author's intent in the text, there is no perfect interpretation of the text in the reader. Nevertheless, interpretation is the only way to engage with and understand the text, and to do justice to the text and the author. Similarly, the patient's narrative is constituted by all the features of the patient, from testimonial expressions to their desires, and from their familial relationships to the institutions they are subject to. Clinicians who engage with the patient are involved in a process of interpretation, which is at the same time imperfect and necessary. This process of interpretation is what allows for understanding, and it's this understanding of the patient that is prerequisite for dignity.

**Are There Necessary and Sufficient Conditions for Narrative?**

Given the broad understanding of narrative and its role in grounding relational dignity, it's relevant to consider the necessary and sufficient conditions for narrative. This question becomes increasingly relevant in cases of diminished capacity. As we'll see in the next chapter, Ronald Dworkin argues that in certain cases of mental decline, the person loses their ability to value (1993). While Agnieszka Jaworska resists this claim for many of the cases (2005), the discussion emphasizes the importance of the question, Are values a necessary condition for narrative? Here, it helps to (re)distinguish between autonomy and dignity, and the different ways Dworkin and Jaworska use these terms.

- Independent autonomy: the ability to value, critically assess one's values, and act in accordance with those values, without any assistance. This is what Dworkin understands autonomy to be full stop.
- Autonomy: the ability to value, separate from the capacity to critically assess one's values and/or act on those values without assistance. This is what Jaworska understands autonomy to be.
- Universal dignity: the value we have in virtue of being a human being. This is what Dworkin simply calls dignity.
- Narrative-based relational dignity: to have one's narrative responded to appropriately in (surrogate) decision-making and action.

The foundational role of values in autonomy and the traditional connection between autonomy and dignity may lead us to believe that values are a necessary condition for relational dignity. Nevertheless, I argue that they are not. While values are required for autonomy, the entire point of relational dignity is to set standards for deciding and acting that are not contingent on autonomy. The presence of contemporaneous values are a significant part of both relational dignity and autonomy, but they are necessary only for autonomy.

If values are not a necessary condition for narrative, then what is? Like Killmister, I resist reducing dignity or narrative to a set of necessary conditions (Killmister 2020a, 3). There no doubt comes a point at which we can rightfully ask of the being that decidedly had a narrative, whether it at present has one given its decline. Or where we can identify beings that potentially have a narrative, and wonder about the limits. I do not mean to minimize the significance of these questions. However, since this project is focused on a clinical context, the presumption should be in favor of the presence of narrative and dignifying the patient. Furthermore, I think that in any case where we might rightfully wonder about the presence of narrative, we have reason to be permissive in our judgment. In other words, I am hesitant to specify any features of narrative as necessary conditions, because I think that its expansive description has powerful potential, on which I discuss further at the end of this chapter.

C. Narrative-Based Relational Dignity

This section will utilize the discussions of the foregoing relational accounts of dignity from chapter 2, as well as the explication of the notion of narrative from the previous section, in order to specify the narrative-based account of relational dignity. Like Luban’s account, it grounds dignity in something like a person’s story. Unlike Luban’s account, it offers a more thorough development of the nature of narrative. Like Killmister’s account, it aims at universality, vulnerability, and achievement. Unlike Killmister’s account, it does not—at least at this stage—attempt to be unifying, and instead provides a more particularized and potentially expansive grounds of dignity than norms. Like Barclay’s account, it attempts to avoid the over-intellectualization of
dignity, and is particularly concerned with healthcare settings. Unlike Barclay, the aim is for this account to be broadly applicable in (applied) ethics and provides more content to what it means to treat someone as a (social) equal. As previously stated, in order to develop this account of relational dignity, it is helpful to distinguish it from universal dignity. While we need an account that captures the universal ascription of dignity in an appropriate way, this will not be the same kind of metaphysical dignity we see come out of the broadly Kantian tradition, nor will it be left empty as in the liberal human dignity convention. One concern might be that this view does not provide for the basic moral status of people, a significant benefit of universal dignity and Killmister’s account. However, on the narrative-based relational account of dignity, having a narrative is sufficient for moral status. The view is silent on whether this is the exclusive basis of moral value. This is, first, because there is insufficient room to offer such a metaethical account, and two, because I want the view to be inviting and acceptable even for those who already hold a particular view of basic moral status. This account of relational dignity is also distinguished from status dignity at least insofar as the latter is a broader category that may include many kinds of non-moral normative standards. Ultimately, all accounts of dignity are concerned with the recognition of some kind of status, but for the purposes of this project, I am to treat both universal dignity and relational dignity as distinct.

Relational Dignity

Relationality can mean many different things, a fact that becomes clear when we look at the role of community in the aforementioned relational accounts. Luban specifies that “having human dignity means being an individual self who is not entirely subsumed into larger communities” (Luban 2005, 838). This fits with his understanding of dignity as ultimately grounded in a person’s point-of-view. Complete subsumption would mean that the point-of-view would no longer be the person’s own. They would have no point-of-view, no story, and therefore no standard with respect to that story that can be violated. However, recall that for Killmister, subsumption within the larger community is how she is able to save the universality of her account. When personal values fail, for instance due to severe cognitive impairment, the default back to the larger community’s values is what allows us to enforce standards of dignity (Killmister 2017, 2077). Finally, for Barclay, dignity is about breaking through the social schemas which “[fail] to treat people with cognitive impairments as our social equals” (Barclay 2018, 66). In this case, the person’s social environment is both what perpetuates the vicious cycle of the schema, as well as the key to breaking through it.

As we have seen, for Luban, dignity is relational. It is not inherently tied to agency, autonomy, or virtue; rather, it concerns a person’s social environment and how they are treated within that environment. Mainly, for someone to be treated
with dignity is for them not to be humiliated. Luban explicates this understanding of
dignity in terms of a person's story and their ability to control how they represent
themselves. This notion of “story” is insufficient and must be expanded. Killmister, by
contrast, develops the grounds of dignity in terms of personal and social norms.
Narrative, as I understand it, involves these personal and social values, though it's not
a mere combination. Where Killmister’s account suggests that in the absence of
personal values we default to social values, my account of narrative is more sensitive
to the relevant evidence in a particular situation and to the totality of features that
constitute the structure of a person’s life. The narrative-based relational view of
dignity holds that (1) every person has a narrative that is comprised of the features
that together constitute the structure of a person’s life, and; (2) that dignity is realized
when someone’s narrative is responded to appropriately in actions or
decision-making that affect this person. Dignity on this account is relational in a very
literal sense. It is transitive, like being understood. To be understood requires an
interlocutor that understands. In order to be dignified, our narrative doesn’t merely
require expression or utterance, it requires uptake.

A person’s narrative entails a standard for deciding and acting that, when it is
met, dignifies that person. This definition requires some unpacking. Standard means
that the account is normative. Standards are measures that must be lived up to, and
failing to measure up entails an undesirable deviation. Deciding and acting entails a
social dimension. We can of course decide and act for ourselves, but here we are
concerned with decisions and actions that affect others. They can do so in broadly
two ways. First, our decisions and actions generally affect other people, and ethics
concerns these interpersonal perturbations. Second, in the context of people with
diminished capacities, there may be a need to decide in their stead. On this view,
dignity becomes about the relationship between the individual that is deciding or
acting, and the person that is affected by this exercise of agency—i.e. the person
being acted upon—or the person that is being decided for. The relevant standard is
relativized to the person’s narrative, and concerns how our actions, desires, values,
preferences, relationships, environment, and so on together constitute the structure
of lives and shape our decisions.

Based on this quick definition of the view, one might conclude that on this
account to have a narrative is to have dignity, and that this dignity must be
respected. This is recognition respect—one is recognized as having a narrative. This is
inaccurate and reflects the ingrained disposition to view dignity as an inherent
property. Instead, the account understands narrative as the grounds for dignity, as a
necessary and sufficient condition, and dignity comes about through the
appropriate response to dignity. Here, dignity is a success condition, and actions can
be either dignifying or undignifying, depending on their narrative fit, where narrative
is the structure of a person’s life. This still requires recognition respect, insofar as one
has to be recognized as a being with a narrative. However, what dignity as such
requires is appraisal respect, i.e. the appropriate response to the features that constitute one’s narrative.

This explication of dignity, first, centralizes the concern with dignity in the action itself. Actions are not responses to dignity, but rather realize it. It makes clear the intimate connection between social relations and dignity. Consider the conditions in Abu Ghraib. The question as to whether these prisoners had dignity sounds misplaced. On the universal account, of course they did, but nothing about their treatment suggests it. So the assurance that someone, despite all of this mistreatment and humiliation, still possess dignity seems of little reassurance. Rather, the idea that they were stripped of their dignity rings with validity. We might be tempted to say they were stripped of their humanity, but this is conflicted. It is precisely because they were recognizes as humans with a narrative, that is, with desires, preferences, values, and relationships, that makes the act of torture intelligible. We cannot torture a rock. Torture is torture precisely because it recognizes the person as a being with narrative, and then systematically violates that narrative. This also emphasizes the relational role of dignity, where dignity is the status of having one’s narrative responded to appropriately. That is, when we express relational dignity in terms of status, the status itself is relational. In short, relational dignity is a standard for action or decision-making that is grounded in narrative. A narrative is the structure of a person’s life, including testimony, actions, preferences, values, relationships, and institutional ties. To dignity a person requires that actions and decisions fit with their narrative.

(Only) Standing in Relation to Oneself and Other Worries

This view of dignity has potential consequences for how we ought to act toward and decide for ourselves. That is, we can violate our own dignity insofar as we can violate our own narrative. For instance, someone who strongly identifies with the part of their narrative connected to their conservative religious upbringing may be humiliated if under the influence of alcohol they act promiscuously in public.\(^{26}\) It is also possible to stand in a dignifying relation to one’s self. In a sense, then, we can be our own interlocutor. This may sound like a stretch, but we often stand in this kind of relation to ourselves. Most of the time, this happens implicitly. When we make the small day-to-day decisions that generally reflect our desires, preferences, relationships, and so on. Other times, there is a more obvious deliberation about what we should do. For instance, when we pick a major or career path, when we try to figure out if someone is the right partner for us, whether we should have kids,

\(^{26}\) The claim here is not that public promiscuity is wrong or humiliating full stop. Rather, the point is that people’s narratives may include standards that they themselves violate.
where to move to, etc. These kinds of life-changing decisions can make us think through the structure of our life so that we can make a decision that is dignifying.

What does the framework entail for those who lack a narrative? That is, the framework ties dignity to narrative in a way that seems exclusionary of anyone that does not have a narrative, and we may worry that this makes the account limited in exactly the way the account is trying to avoid. Fortunately, the contrary is true, and this view is very inclusive. It has the potential to extend to animals and the environment, and may even apply to (recently) deceased individuals. Even if some of the narrative elements are missing, as long as others are present we can speak of narrative, and by extension dignity, in a meaningful way. In spite of potential limits on narrative, or difficulties accessing narrative, there are still grounds for consideration and dignity.

A further worry stems from the relational nature of dignity. This seems to exclude certain people from consideration. For instance, a solitary monk, a curmudgeonly hermit, or even a Tom Hanks-like character from Cast Away (2000). However, this view does not exclude reclusive individuals. For one, the view allows that the recluse could potentially fail to dignify themselves by violating their narrative standards. For instance, they could be a highly sociable person who forces themselves away from people. However, the framework focuses on interpersonal conduct, and in this sense, it may be limited in application. There are two important points to make about this. First, depending on specific narrative features, the view may have something to say about whether the person should remain in isolation, or whether others should attempt to get them out of their situation. Second, we would expect limited applicability in this case. Insofar as ethics is (primarily) about what we owe others in interpersonal conduct, there is less to say about those who avoid, whether out of principle, necessity, or circumstance, such interactions.

Finally, we may be concerned about the potential consequences the account has for people whose relationships, on the whole, are unsatisfactory. What does it mean if all of someone’s social, and perhaps institutional ties, are lousy? The view does not merely look at the extant relationships as value-free commitments. Rather, the status of those relationships as being good, productive, supportive, reciprocal, etc. or their opposite are relevant as well. This means, for instance, that the structural and institutional racism that affects Black Americans is relevant to how we interpret their narrative and decision-making. Here, the notion of “moral security” is relevant, as discussed borrowed by Killmister from Jessica Wolfendale (2017):

Broadly speaking, a person possesses subjective moral security when she believes that her basic interests and welfare will be accorded moral recognition by others in her community and by social, political, and legal institutions in her society. She possesses objective moral security if, as a matter of fact, her interests and welfare are regarded by her society as morally
important—for example, when violent crimes against her are taken to warrant the same punishment and condemnation as equivalent crimes against others. (Wolfendate 2017, quoted in Killmister 2020a, 110, italics added by Killmister)

Being a patient is to be in a vulnerable position. The responsibility for the care of your physical wellbeing is transferred, often to multiple other persons with whom you have little to no personal relationship. In this situation, one’s moral security can be affirmed or eroded. Some people come into a healthcare setting with a high level of objective and subjective moral security. In the United States, a wealthy white male in the public eye may reasonably expect his interests to be recognized and respected. By contrast, Black Americans who enter healthcare settings continue to experience the erosion of both subjective and objective moral security. There are innumerable accounts and anecdotes receiving inequitable care, having their pain ignored, and experiencing higher risks of mortality, in particular in childbirth. In this context, Black Americans may well feel unsafe and anticipate this lack of uptake, and in fact experience it. That is to say, the distrust and wariness of the physicians expressed by Black Americans doesn’t mean they’re paranoid or conspiratorial. Given the history of the treatment of Black Americans in the medical system, the ongoing disparities in health outcomes, pain management, and the racial disparity in childbirth mortality rate, these concerns are valid and rational.

Meeting the Desiderata of Dignity

Killmister specifies three desiderata that a concept of dignity must meet in order to “accommodate the core uses to which the concept is put in everyday discourse” (Killmister 2020a, 13, 14). First, the view must make clear that and how “dignity has something to do with the respect people command” (Killmister 2020a, 14). Second, it must account for the ways in which “dignity is a variable quality” (Killimster 2020a, 15). Third, it must allow that “dignity is the kind of feature that can be damaged, or persons can be stripped of” (Killmister 2020a, 15). Respectively, these are the desiderata of respect, variability, and vulnerability. Meeting these desiderata is an indicator of the framework’s success in capturing the different ways in which we use “dignity” in common discourse. How does the narrative-based account of relational dignity fare with respect to these requirements?

First, respect. Narrative-based relational dignity involves both recognition and appraisal respect. First, one must be recognized as a being with a narrative. Second, one’s narrative is subject to appraisal respect. In respecting the features of a person’s narrative, the person is dignified. Second, variability. Narrative-based relational dignity is variable. We can do better or worse at responding fully and appropriately to someone’s narrative. Third, vulnerability. Narrative-based relational dignity is vulnerable, though possibly not in the same way Killmister proposes. There are two
ways to interpret Killmister on vulnerability which affects how we understand dignity. According to Killmister, dignity can be damaged, which presupposes dignity as an extant property that a person has. This dignity can subsequently be strengthened through ennobling actions or weakened through damaging actions. Alternatively, we can see dignity as being realized in the affirmation of the norms. So for Killmister, does a person have dignity in virtue of the norms, or as a result of the response to the norms? This is ambiguous. If the former is accurate, then Killmister and I have a different understanding of the vulnerability of dignity. If the latter is accurate, then we conceive of vulnerability in roughly the same way. Regardless, on the proposed account, dignity is vulnerable insofar as we can fail to respond appropriately and thereby undignify or disrespect people.

**Respect, Autonomy, Humiliation, and Paternalism in Relational Dignity**

This narrative-based relational account of dignity allows us to give content to important dignity-related terminology. On this view, to *respect* a person means to treat them in a way that fits with their narrative. This can also be expressed in terms of the verbification of the noun, i.e. to *dignify* a person is to treat them in a way that coheres with their narrative. Basic autonomy refers to the subset of autonomy-related capacities, including the ability to value and have preferences. This may require various kinds of support from the individual’s environment, but what is relevant for this notion of autonomy is that the person can live their life according to their own vision of what their life should be like. Independent or advanced autonomy is the capacity to decide and act based on one’s narrative. These two different notions of autonomy are not mutually exclusive. They exist in a dynamic domain of capacities that can vary over time and per decision or action. That is, someone can be fully independently autonomous with respect to their decision to cook spaghetti for dinner, but may need support inorder to get out of bed in the morning.

On this view of relational dignity, humiliation and disrespect can occur when someone’s dignity is violated, and violations of dignity occur when someone is treated in a way that is contrary to their narrative. Disrespect is the more descriptive notion, whereas being undignified or humiliated has a stronger normative and phenomenological component. In general, paternalism refers to the exercise of authority by the controllee motivated by the best interest of the controlled. In other words, someone’s autonomy is limited in order to protect or advance their own best interest. In the context of surrogate decision-making, however, paternalism is best understood as deciding in a way that does not (sufficiently) respect the individual’s narrative.
D. Narrative-Based Relational Dignity through the Cases

Dignity at the End of Life

We have already seen a number of case studies throughout this project, analyzed according to different relevant views. Since the narrative-based relational account of dignity is meant to help evaluate and resolve cases, it makes sense to use case studies to demonstrate how this view transforms our understanding of them. The next chapter continues this exposition, by focussing on surrogate decision-making in the context of Alzheimer’s disease. For now, we'll start by looking at the case we evaluated earlier in the section on narrative, namely (How) Do We Choose Our End? However, I present it here in an expanded format, so as to include more narrative-based information. This is closer to how the case was originally presented by Timothy Quill in “My Patient's Suicide” (1991a, 32-33).

Case—(How) Do We Choose Our End? (Expanded)

Diane was a vaginal cancer survivor, someone who has struggled with depression, who is nearly four years sober, a business owner and artist, and has over the last few years deepened her relationships with friends and family. She had come to see Dr. Quill because she “was feeling tired and had a rash.” As it turns out, “Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells.” When Quill called Diane, he “reluctantly opened the door to leukemia. Hearing the word seemed to make it exist. ‘Oh, shit!’ she said. ‘Don’t tell me that.”

Quill researched her options at length, and found that a series of chemotherapy treatments would ultimately give her a 25% chance at survival, whereas abstaining from treatment would mean “certain death in days, weeks, or months.” The situation was so severe that the oncologist had planned on starting chemotherapy the same afternoon that they informed Diane of the diagnosis. Diane, however, was “enraged at his presumption that she would want treatment and devastated by the finality of the diagnosis.” In the following days, it became clear that Diane understood her options, the risks and benefits, and was steadfast in her decision to not undergo treatment. “Her family wished she would choose treatment but accepted her decision.”

Over time, it became clear that Diane did not want to “linger,” but wanted to “maintain her dignity during the time remaining to her” and “When this was no longer possible, she clearly wanted to die.” At Quill’s direction, Diane
researched her options via the Hemlock Society, and soon requested a prescription for barbiturates to aid with sleep. When Quill met with Diane, it was clear that she could use a sleep aid, but that she also wanted "the security of having enough barbiturates available to commit suicide, if and when the time came," because this "would give her the peace of mind she needed to live fully in the present."

Quill relays: "I made sure that she knew how to use the barbiturates for sleep, and how to use them to commit suicide. We agreed to meet regularly, and she promised to meet with me before taking her life. I wrote the prescriptions with an uneasy feeling about the boundaries I was exploring—spiritual, legal, professional, and personal. Yet I also felt strongly that I was making it possible for her to get the most out of the time she had left."

Several months later, after regular meetings with Quill and quality time with her family and friend, Diane was declining rapidly. They met, and Diane said she "was sad and frightened to be leaving but ... even more terrified to stay and suffer." She died two days later. Her son and husband had "no doubts about the course she had chosen, or about their cooperation."

The expanded format of the case allows us to extract and evaluate the narrative elements of the case in greater detail.

Expressed Elements of Narrative
- Testimony: Diane has expressed that she is not interested in treatment for cancer. She indicates a desire for palliative care in the form of sleep aids, as well as the availability of sufficient drugs to facilitate suicide.
- Behaviors: Diane’s behavior is consistent with her testimony, values, preferences, etc.
- Actions: The patient is actively researching their options.

Personal Elements of Narrative
- Attitudes: The patient has disapprobative attitudes toward the oncologist recommended treatment plan.
- Desires: The patient desires a comfortable end of life with control over the time and place of her death.
- Values: The patient’s values appear consistent with the relevant desires.
- Preferences: The patient prefers a self-regulated death over the natural progression of their disease.
- Understanding: Diane clearly understands her situation and her options. She is making a decision to refuse treatment based on her past experience and an appreciation of the chances of success.
- Medical History: Diane has experience with cancer and treatment, which provides her a uniquely informed perspective.

Social Elements of Narrative
- Diane’s relationship to their family and friends appears good. After becoming sober they have worked to repair and improve these relationships.
- After some initial hesitation, Diane enjoys the support of their family in rejecting treatment. They even reaffirm this after Diane passes away.
- Diane has a fulfilling professional life, with her own business and artistic career.
- Diane has a good relationship with her prescribing physician. It is clear from Quill’s description that their history goes back some time, and the informal language in the conversations he relays suggests that they are on friendly terms.

Structural Elements of Narrative
- There are many structural issues that relate to this case, but most importantly are the professional and legislative constraints that exist in this context. The AMA generally disapproves of physician assisted suicide, and the time and place in which this case is situated entails that there are legal prohibitions against physician assisted dying as well. While these could perhaps be circumvented in the case of a willing physician, if the patient finds themselves admitted to the hospital, active euthanasia will almost certainly not be an option for them.

The narrative analysis makes clear that Diane has intimate knowledge of what cancer treatment can look like, that she understands the details of her situation, and that she makes the decision to refuse treatment from a well informed place. The decision is in line with her long-term attitudes, values, and preferences, and she enjoys support from her social circle. Quill understands her decision, as well as the relevant structural elements. In light of Diane’s narrative, Quill decides that to help facilitate Diane’s suicide is a dignifying decision. This has a significant contrast to the case Mrs. Rogoff’s Change of Heart? (from Jaworska 2005, 105-106), which demonstrates how the structural features of the case can make a deciding difference, and that as a result recent and current attitudes and desires can be decisive. This case is discussed at length in the next chapter.
Dignity and the Role of Irrationality

It seems that this account, in centering the desires and preferences of an incapacitated patient, may open the door to support irrational decisions. The relational account of dignity centers the features of a person that are central in decision-making, including their testimony, desires, preferences, and values. Ordinarily, these are the features of a person that determines autonomous decision-making. In the case of an incapacitated person, they are for whatever reason unable to decide for themselves. This is, generally speaking, due to an aberration in a subset of their capacities. For instance, the comatose person is unable to express their preferences or values, and someone who suffers from early stage dementia might have trouble with memory and means-ends reasoning. Diminished capacity in these areas, however, does not support neglecting the full range of capacities the person has. If they have stable preferences over time, an intelligible set of values, or relationships that evidently matter to them, then there is no reason not to take these features up in the process of surrogate decision-making. In fact, this account concludes that this is morally required. However, this does not entail that every narrative element must be determinant in the outcome of decision-making. Recall the case of Mary Beth, who believed that Dolly Parton would take care of her post discharge. The fact that this expression was based on confabulation means that this belief, no matter how sincerely held, cannot be taken up in the discharge plan.

The understanding of narrative developed in this project is sensitive to both internalist and externalist consideration in decision-making. This is not to say that irrationality can never play a role in decision-making. For instance, I may have an irrational fear of biopsies. This is based in a deep-seated belief that biopsying a cancerous growth will lead to its rapid metastasis. The belief is not reason-responsive, and so I am unable to address this fear. In light of this, I refuse a biopsy that my oncologist is recommending. The belief and the decision are both irrational, but I can acknowledge them as such. Furthermore, I understand the dangers in refusing the biopsy, and it is clear that I am in general capacitated to make this decision. In such a case, the irrational decision would be supported by the framework, because of the way the irrational fear is contextualized in the other narrative elements.

In other cases, two decisions that may look very similar and irrational, may be evaluated by the framework in very different ways. Indeed, the framework is meant to be able to balance internalist and externalist considerations with respect to rational decision-making. To illustrate this ability, let’s consider two superficially similar, yet contrasting cases.
Case—*The Jehovah’s Witness*\(^{27}\)

Kelly is a Jehovah’s witness who is suffering from renal cancer. She needs a radical nephrectomy, but the surgery is expected to come with significant blood loss and the need for transfusion. Kelly is a Jehovah’s witness, and according to her religious beliefs cannot receive a blood transfusion. Performing the operation without blood transfusion will likely result in death, as will refusing the surgery. Let’s assume that no alternative options are available. Should Kelly’s decision to refuse a blood transfusion, no matter the consequences, be respected? The oncologist has requested a psychological evaluation, which concludes that Kelly is capacitated to make this decision.

Since it has been established that Kelly has capacity, it is clear that she understands her condition, the risks involved, and understands the nature of her conviction. That is, she knows that her decision is motivated by religious faith, that there is no certainty about whether this belief is accurate, and so on. Rather, like all convictions, it is a structural part of Kelly’s life, and she is choosing to decide accordingly. In other words, the refusal of blood transfusion is motivated by Kelly’s values and preferences, as well as her relationship to her faith and her connection to its institutions. While she is supported in her decision by friends and family, she does not appear to be coerced in this decision by anyone, and is accepting the risks from a position of being well informed. To overwrite Kelly’s decision would not only be a violation of bodily autonomy, but of her narrative.

*Case—Jesus at Bedside*

Shelly is a retired nurse practitioner. She came into the hospital after she collapsed at the grocery store. An MRI revealed that Shelly is suffering from XYZ cancer, which requires an operation. Shelly refuses the operation, explaining that Jesus came to her bedside and told her she would be healed. The oncologists request a psych consult, which determines that Shelly is suffering from delusions and is incapacitated. In conversations with visiting family it becomes clear that Shelly is not acting like her usual self. While she attends church regularly, she is not particularly devout, and has never before spoken of an encounter with the Son of God. Moreover, it appears that Shelly’s refusal of the surgery is solely motivated by Jesus’ message.

\(^{27}\) Some details of this case were solidified with reference to (Vandever 2018, n.p.; Cata and Gottumukkala 2012, n.p.).
Looking at Shelly’s narrative, we can see many elements that favor treatment. Moreover, it looks like the elements that weigh against treatment are informed by a false belief that appears to be produced by her condition. Overwriting Shelly’s decision in this case seems to appropriately respond to her narrative, which includes matters of fact about the world and her condition. Of course, this can be approached in different ways. Depending on the type of delusion, perhaps Shelly can be convinced that she would be healed through the surgery. But either way, to let Shelly die based on a pathological delusion that is out of sync with her narrative is undignifying. In short, irrationality is neither supported nor excluded from the framework, but contextualized against all features that constitute the structure of a person’s life.

**Recently Acquired Disability, Deciding to Die, and Sour Grapes**

Narrative is at least in part based on self-knowledge. But self-knowledge can be flawed, which means that if we prioritize the first person perspective, then we may be enabling people in their own self-oppression. For instance, someone who has acquired a significant disability may be making decisions based on their own ableist biases. How does this framework support navigating decision-making in cases of recently acquired disabilities? How do we distinguish between cases where a patient needs time to adjust and ones where a patient needs to have their end-of-life decision respected? And how do we do this while guarding against the paternalist sour grapes objection against disabled people who claim to be happy?

I argue that the difference lies precisely in their narrative, and in part in the features of narrative that point to facts outside of the individual’s situations. What good medicine and a good clinical ethics framework does is acknowledge and respect the individual while keeping an eye on the body of knowledge that has accumulated over the last decades and centuries. Physicians need to listen to, understand, and respect the patient, while also understanding the medical data. This can be a tricky balance, and often it lapses into paternalism due to a move toward the structural and away from the individual. But resisting this paternalism doesn’t mean that the structural doesn’t play a part. Our understanding of narrative specifies the structures one is subject to as one of its primary components.

Part of what this forces us to recognize is that no case truly stands alone. This is after all why it makes sense to create, sustain, and contribute to a “body of work”—a literature—in clinical ethics, that consists, among other things, of case studies. Some of the most productive clinical ethics discussions I’ve seen and participated in were those that were supplemented by the literature. And I say supplemented, because references to other cases can go both ways: they can support or detract from a potential course of action. The two amputation cases make this very clear. The UTMC Ethics Committee (2018) disagreed with how Wasserman
and Navin (2018) analyzed the case, and precisely this disagreement played a part in how the committee approached their case.

Let’s briefly look at two other “competing” cases, concerning the treatment of and surrogate decision-making for burn victims. In “Getting Past Dax” (2018), Monica L. Gerrek argues in favor of broadening the analytical scope of burn victim discussions past that of Dax Cowart’s famous and precedent setting case. She does this by offering the remarkably similar case of Andrea Rubin. Gerrek recounts their stories as follows.

Case—Dax Cowart and Paternalism in the Burn Unit

In 1973, 25-year-old Dax Cowart, former captain of his high school football team, former Air Force pilot, rodeo rider, and aspiring commercial pilot, was severely burned as a result of a freak accident. Dax’s father had inadvertently parked his car on a bridge over a leaking propane pipe, and a spark from an attempt to start the car caused an explosion. His father was killed and Dax suffered a burn to 65% of his total body surface area (TBSA), with third-degree burns to his face, ears, and hands. Most of his fingers were amputated and he lost vision in both eyes. His words to the first person, a farmer, who arrived at the scene were, “Get me a gun. Can’t you see I’m a dead man. I’m going to die anyway.” During his very painful 14 months of treatment—6 in the hospital and 8 in a rehabilitation facility—Dax repeatedly requested that the team discontinue treatment. He asserted that he did not want to live “as a blind and crippled person” and demanded that he be permitted to die even though his mother was consenting to treatment. According to Dax, his physicians generally ignored these requests even after he was deemed to have decision-making capacity by a respected psychiatrist. (Gerrek 2018, n.p., citing Burton 1989 1-12; Cowart 1988 165-9; Coward and Burt 1998, 14-24; Coward 1994, 744-5, and; White and Engelhardt 1975, 9-10, 47)

Case—Andrea Rubin and Decision-Making in the Burn Unit

In 2014, Andrea Rubin was a 49-year-old health insurance sales representative. She had just started this job, having previously been employed in marketing and advertising, and was looking forward to her first busy season. One evening, as she was turning around in a parking lot, her car got stuck after a tire slipped off the pavement. As she tried to dislodge the car by alternating between drive and reverse, the motion caused a spark that set the car on fire. The inside of the car quickly filled with carbon monoxide and she lost consciousness. Andrea suffered a 58% TBSA burn with third-degree burns to her face, ears, head, chest, arms, back, and legs. She suffered fourth-degree
burns to her lower right arm, which was subsequently amputated just below the elbow. She also lost partial vision in her right eye. Her scalp was so badly burned that her hair will never regrow. Her father, like Dax’s mother, consented to treatment. Yet, while Andrea was sedated for approximately two months to promote healing and could not participate in decision making, her friends repeatedly pleaded with the team to discontinue treatment and let her die. They were adamant that “she would not want to live this way” and that she would refuse treatment were she able to express herself. Given her father’s legal standing as her next-of-kin surrogate and his continued support of treatment, the pleas of Andrea’s friends went unheeded. Andrea ultimately spent three months in the hospital and two months in rehabilitation and continues to seek outpatient treatment for her burn injuries. (Gerrek 2018 n.p., citing Gerek, Rubin, and Schirokauer 2017, and; Rubin 2018).

The cases of Cowart and Rubin are as remarkably similar as they are different. The similarities would suggest that we ought to produce similar judgments about their care, and subject either Coward or Rubin to extreme paternalism. That is, either the medical team was correct in their judgment about continuing care despite the protests of Cowart and Rubin’s friends, and therefore were right to overwrite Cowart’s explicit wishes, or they were wrong in their judgment about continuing care, and should have abstaining from treatment in both cases, which would have wronged Rubin retrospectively.

However, as often is the case, the details are incredibly important. A notable difference is that the doctor’s refused to discuss end-of-life options for Cowart even after it had been established that he was capacitated to make that decision. Moreover, the fact that they experienced their rehabilitation in radically different ways is relevant information that is not merely accessible in hindsight. This experience would help validate judgments about treatment decisions.

It’s important to emphasize that this kind of data plays a key role in interpreting someone’s narrative. In “Resilience and Happiness After Spinal Cord Injury” Duggan et al. report the results of a qualitative study on “factors associated with resilience among individuals with spinal cord injury (SCI)” (Duggan et al. 2016, n.p.). The results suggest that “respondents with SCI identified themselves as happy and explained their adjustment and resilience as related to personality, good social support, and a spiritual connection” (Duggan et al. 2016, n.p.). One of the implications they recognize, is that “It is important that clinicians integrate into practice not only information that is based upon studies that demonstrate statistical relationships among and between variables but also information from the narrative qualitative approach that adds an understanding of the process of ‘successful adjustment.’” (Duggan et al. 2016, n.p.)
In 1978, Philip Brickman, Dan Coates, and Ronnie Janoff-Bulman published the influential “Lottery Winners and Accident Victims: Is Happiness Relative.” They conclude there is good evidence that suggests that “happiness is relative” and while there are “meaningful variations in people’s judgment of the quality of life” it is not clear what underwrites these (Brickman, Coates, and Janoff-Bulman 1978, 925, 926). They suggest that that in the absence of such an account, “we tend to overestimate the magnitude, generality, and duration of other people’s feelings” in particular in response to life changing events, whether *prima facie* good or bad (Brickman, Coates, and Janoff-Bulman 1978, 926).

This article sparked a surge of research into the phenomenon of hedonic adaptability, or the idea that “people tend to adapt fairly quickly to the state they are in, good or bad, and adjust their baseline utility accordingly” (Mitchell 2018, 1003). This thesis in turn raises a lot of questions, about the objectivity or subjectivity about happiness, the authoritativeness of the testimony of disabled people, the role of lived experience in philosophy of disability, and so on. While some of the results of the Brickman, Coates, and Janoff-Bulman paper are controversial, the disability literature is moving toward greater acceptance of lived experience as not merely valuable but invaluable data. And this data suggests that, through whatever mechanism, happiness levels tend to return to something approaching baseline following an adjustment period after the acquisition of a disability. For instance, Peter A. Ubel, George Loewenstein, and Christopher Jepson, in “Whose Quality of Life? A Commentary Exploring Discrepancies Between Health State Evaluations of Patients and the General Public” (2013), conclude that “whatever makes up happiness or quality of life, it appears that many illnesses have far less impact on subjective quality of life than many of us would predict” (Ubel, Loewenstein, and Jepson 2013, 605).

Polly Mitchell, in “Adaptive Preferences, Adapted Preferences” (2018), discusses the disability paradox, the notion that “People who have not experienced diseases, disabilities and health conditions tend to judge them to be worse than they are reported to be by people who have experienced them” (Mitchell 2018, 1003, citing (Ubel et al. 2005). Mitchell notes that one of the possible resolutions of the paradox is the notion of adaptive preference, or “the common assumption that adaptation leads to malformed or irrational preferences” (Mitchell 2018, 1004).

Ubel et al., however, suggests that while “Much more work needs to be done to explore potential sources of bias in the QoL and mood reports of people with chronic illness and disability ... so far it appears that the disability paradox cannot be blamed solely, or even primarily, on patient misreports” (Ubel et al. 2005 S60). Rather, “it is necessary to explore why healthy people might mispredict what their QoL would be if they experienced chronic illness or disability” (Ubel et al. 2005 S61).

---

28 An elaborate discussion of this issue is available in the dissertation of H’Sien Hayward (2013). 107
Ron Amundson, in “Quality of Life, Disability, and Hedonic Psychology” (2010), takes a strong stance with respect to hedonic preferences, noting that “current evidence is unequivocal with respect to the QOL [quality of life] of disabled people” insofar as “hedonic adaptation produces real changes in QOL, not false consciousness” and that in general “the high QOL reports of disabled people are accurate” (Amundson 2010, 289).

Clifton, Llewellyn, and Shakespeare emphasize this point as part of their qualitative study of people with quadriplegia in “Quadriplegia, Virtue Theory, and Flourishing: A Qualitative Study Drawing on Self-Narratives” (2018). They develop their analysis in the context of virtue ethics, looking at eudaimonia as “lifelong flourishing” (Clifton, Llewellyn, and Shakespeare 2018, 21). They use “participants’ own words to weave together a complex narrative showing how people find meaning” (Clifton, Llewellyn, and Shakespeare 2018, 21). This is a much more narrow understanding of narrative, more akin to testimony. Nevertheless, their conclusion is meaningful to our discussion here. They state that:

The narratives show that positive attitudes – which the tradition incorporates as virtues – are central to resilient flourishing with quadriplegia. To this end, participants drew on experiences and capacities developed prior to the injury. But to manage increased dependency, they were also required to develop existing virtues and learn new ones, such as the virtues of friendship and interdependency: gratefulness, friendliness, patience, forgiveness, interpersonal wisdom, and so on. The participants understood that life is a journey replete with joys and sorrows, and that lifelong hardships can be navigated by exercising positive virtues such as optimism, hopefulness, and determination and by focusing on what is possible rather than impossible. (Clifton, Llewellyn, and Shakespeare 2018, 35)

What’s vital here is that, as the authors emphasize, these stories are not “inspiration porn,” rather, these stories “show the up-and-down messiness of living with quadriplegia, and reveal some of the virtues needed to live a more up than down life, and so over the longer term to flourish” (Clifton, Llewellyn, and Shakespeare 2018, 36, citing Young 2012).

Mitchell draws out an important point at the end of his conclusion that speaks to this, namely that “adaptation should not be regarded as an exceptional phenomenon: all preferences are contextually anchored to some extent, and as such responsive to environment and circumstantial change” (Mitchell 2008, 1022).

29 In “Faith, Spirituality, and Living the Good Life With Quadriplegia” (2020), the same authors discuss the effects of religion on people’s qualitative assessment of their lives. While they still contextualize this in terms of virtue ethics, it is clear that these features of people’s lives are also part of their narrative, construed as on the account proposed here.
The famous burns case, the data on people with acquired disabilities and their happiness over time, our very best understanding of the nature of Alzheimer’s disease and its effects on identity (discussed in the next chapter), these are all data and facts that inform the particular patient’s narrative and our interpretation of their narrative. And while this should not permit rampant paternalism, it may support paternalist decisions that allow for better future decision making by the patient.

Part of this concerns understanding narrative as a changing thing. Often, its parts change slowly over time, and not each at once. But occasionally, a dramatic change will affect someone’s entire narrative. Acquiring a disability, burning a large percentage of one’s body, being the victim of horrific violence. In her autobiographical philosophy monograph *Aftermath* (2003), Susan Brison discusses the narrative-destroying nature of the latter. Of course, parts of the person’s narrative remain, but in these cases it’s the internal, personal, experiential elements that become disrupted. And these parts are ordinarily central in decision-making. So it’s not that in the aftermath of these events there is no person there. But the person is distorted, disrupted, fragmented. Brison talks about her experience in a “rape survivors’ support group” where she was told that she would “never be the same” but that she could “be better” (Brison 2003, 115). She concludes that agrees, “Not ‘better’ in the sense of having a life that’s more coherent, in control, predictable. But ‘better’ in the sense that comes from acknowledging that life is a story in the telling, in the retelling, and that one can have some control over that” (Brison 2003, 115). The radical disruption to so many elements of narrative requires a time of rebuilding, recovery, and resituating. Victims and patients need time to make sense of their situation and of themselves in it. Perhaps, as for Brison, it requires confronting a lack of metaphysical selfhood that was always already there, concealed by an illusion of rational order and meaning (Brison 2003, 115-6). Understanding this means that care providers are charged with facilitating this process to the best of their ability.

The foregoing discussion of Dax Cowart and Andrea Rubin shows that people can have radically different responses to strikingly similar situations. The hedonic adaptation literature shows this as well. All this data contributes to how we ought to evaluate the expressed preferences in any individual instance of surrogate decision-making. For instance, Cowart’s preference to bring about the end of his life does not seem to have been motivated by an ableist bias. Rather, the tortuous condition he was in and was expected to be in for the foreseeable future made him adamant, both immediately following the accident and months later when decision-making capacity had been confirmed, that he wanted to die. This is notably different from Rubin’s case, who was generally in good spirits once she regained consciousness. In the hedonic adaptation cases we can certainly see that for some people who become disabled their primary concern is one of dependency. Understanding this can help us weigh the complete set of motivations in surrogate decision-making. What is important to emphasize, is that this account of dignity
requires being open to the possibility of physician assisted dying being the dignifying decision for a patient, and—acting is recognition of legal constraints—must be supported in that course of action.

E. Extending Dignity

As noted earlier in this chapter, I am hesitant to specify any features of narrative as necessary conditions, because I think that its expansive description has powerful, extensionist potential. For one, the proposed conceptualization of narrative and relational dignity is able to account for how and why we respect the wishes of people who are (recently) deceased, and for why certain kinds of treatment of people in a persistent vegetative state are wrong. The view also has potential consequences for how we understand animal and environmental ethics.

Dignity After Death

We often think of death as the full termination of the person, along with all of their desires, preferences, and values. We can therefore have a difficult time explaining our intuitions that we should honor that person’s wishes. We may wonder: Am I really harming someone when I fail to make good on their expressed wishes after they have died? Epicurus (c. 341–270 BCE) famously argued that “death is nothing to us, for good and evil imply the capacity for sensation, and death is the privation of all sentience” (Epicurus N.d., n.p.). Here, again, we are referencing questions concerning the metaphysics of identity over time and the badness of death. There is a significant literature on this subject. Though I won’t recount it in detail here, it’s worth mentioning a few key accounts. The Metaphysics of Death (1993) offers a selection of works that deal with this and related questions concerning the nature of death. For instance, in his essay “Death,” Thomas Nagel echoes Epicurus’ claim, arguing that “none of it can be counted as a misfortune for him so long as he does not suffer as a result” (Nagel 1993, 64). This view is also defended by Stephen E. Rosenbaum in “How to Be Dead and Not Care” (1993). He argues that “if a person cannot experience a state of affairs at some time, then the state of affairs is not bad for the person. Dead persons cannot experience any states of affairs; they are blind, deaf, and generally insentient. So no state of affairs is bad for a dead person” (Rosenbaum 1993, 123).

By contrast, Harry S. Silverstein, in “The Evil of Death” (1993), rejects these views by arguing that we should prefer a four-dimensional understanding of the world, on which time is the fourth dimension (Silverstein 1993, 110-11, citing Quine 1978, 7-9). This entails understanding predication and existence as timeless, which entails that “posthumous reference poses no difficulty” (Silverstein 1993, 113). In “The Misfortunes of Death” (1993), George Pitcher argues that “the sense in which an ante-mortem
person is harmed by an unfortunate event after his death is this: the occurrence of the even makes it true that during the time before the person's death, he was harmed—harmed in that the unfortunate event was going to happen" (Pitcher 1993, 168). And in “Harm to Others” (1993), Joel Feinberg argues a similar point, not in terms of reverse-temporal causality (or whatever Pitcher’s claim is), but in terms of “surviving interest” which may be “thwarted after … death” (Feinberg 1993, 188).

Relationality offers a distinct way of approaching these questions. On the relational account, the individual is the locus of the narrative, but a subset of the narrative features are not fully contained by the mind or body of the individual. This is, after all, the very meaning of a relation. It is a property between things, like a string between two objects. We can remove the object, but the string remains. Consider this often cited quote by Henry Scott Holland:

Death is nothing at all. It does not count. I have only slipped away into the next room. Nothing has happened. Everything remains exactly as it was. I am I, and you are you, and the old life that we lived so fondly together is untouched, unchanged. Whatever we were to each other, that we are still. Call me by the old familiar name. Speak of me in the easy way which you always used. Put no difference into your tone. Wear no forced air of solemnity or sorrow. Laugh as we always laughed at the little jokes that we enjoyed together. Play, smile, think of me, pray for me. Let my name be ever the household word that it always was. Let it be spoken without an effort, without the ghost of a shadow upon it. Life means all that it ever meant. It is the same as it ever was. There is absolute and unbroken continuity. What is this death but a negligible accident? Why should I be out of mind because I am out of sight? I am but waiting for you, for an interval, somewhere very near, just round the corner. All is well. Nothing is hurt; nothing is lost. One brief moment and all will be as it was before. How we shall laugh at the trouble of parting when we meet again! (Holland 1910, n.p., quoted from Dalton-Bradford 2014, 212-3)

This quote from a famous sermon is obviously, given the context, religious in nature. But it captures the sentiment well. Death does remove, but not entirely. Not all that was is now gone. Yet, some of the same questions sneak up here. What does it mean to go act against the desires of a person who is now deceased?

The relational account responds that it means that it violates that person’s narrative. And while it’s true that the person is no longer there, elements of their narrative remain. And those can be violated, and in that sense the person can be undignified by how others respond to their narrative. It may be objected that the fact that the person is dead takes the sting out of humiliation. This is true, but that speaks to our intuitions about those cases: it’s wrong to violate the deceased person’s wishes, but it is—all else constant—worse to violate the living person’s wishes. In
general, though, the concern should be with how we can dignify people, rather than hierarchizing wrongness. In the case of a recently deceased person, their relational dignity can be violated in different ways, depending on the relevant features of their narrative. For instance, someone can give permission for organ donation, but specify that they don’t want their organs traded by body brokers. If their organs ended up with body brokers anyway, this would be profoundly disrespectful, because it violates an explicit preference that they expressed prior to their death (see, for instance, Cheney 2006).

As another example, we can imagine that someone passed away in a very busy emergency room after a natural disaster. In turning the emergency room over as soon as possible, the person got left on gurney in the hallway, completely uncovered. It may well be that we have no access to who this person was and what the most personal features of their narrative are like. And for the sake of argument we can assume that this person has no family or loved ones, and not acquaintances otherwise who could learn about their current state. Yet, their current position is highly undignifying, because it violates the social and cultural standard that we have for how we treat people, dead or alive. And because this person was a member of our society, and this membership is part of their narrative, their current treatment is a violation of that aspect of their narrative. I want to emphasize that this is not, as we’ll see is Dworkin suggestion, a poring in of value from the outside (Dworkin 1993, 230). Rather, it is an appropriate contextualizing of the person in their situation. An as-accurate-as-possible interpretation of their narrative.

As noted above, the potential for this understanding of dignity to account for these kinds of cases is an important feature, and I am therefore hesitant to be too demanding with requirements of necessity and sufficiency. Furthermore, we have seen the potential for this account to extend beyond anthropocentrism—another invaluable feature in establishing this account of dignity as relevant in (applied) ethics more broadly. Realizing this potential requires being cognizant of each narrative element that is present.

**Is Relational Dignity Human Dignity?**

We can think of the subtitular question in *three* distinct ways. The first is to ask whether narrative-based relational dignity exists for all human beings. The view offers a standard for deciding and acting that is based on a person’s narrative. Narrative here is broadly construed, to include expressed, personal, social, and structural elements. These features are sufficiently wide-ranging that I anticipate that all human beings have at least some of these elements. And since to dignify a person means to respect or uphold their narrative, all human beings can in principle be dignified.
The second is to ask whether narrative-based relational dignity can account for human dignity the way this concept is used in the liberal tradition. While this lies too far out of the scope of the current project to respond to fully, there are two brief claims I’d like to make in response. One is that it’s possible that human dignity can be accounted for on this view by means of a similar move as that of Killmister, that is, by subsuming what we think of as human dignity and human rights under the structural elements of narrative. That said, the goal of the framework is to facilitate better ethical analysis and decision-making for the individual, which is the locus of the narrative and therefore the foundational constituent for dignity.

The third is to wonder whether narrative-based relational dignity is applicable outside of the anthropocentric. That is, if relational dignity is grounded in the person’s narrative, and narrative is as permissive of a concept as we have seen, then we may wonder about whether and how the concept extends beyond anthropocentric ethics, and what this potential extension means for the plausibility of the account. This discussion is tentative. My primary focus is on how relational ethics can be explicated and utilized in the context of clinical ethics. However, I do think that the framework, as it has been established here, has broader implications. For one, elements of narrative are undoubtedly present in many animals. While animals generally lack language, many do have communicative ability and can express their perspective through actions and behavior. Animals can have desires and preferences, and it appears they are able to value as well (see, for instance, De Waal 2003 and 2012). Animals also have relationships, both to others of their kind as well as to members of other species, and often to humans as well. They also stand in relation to their environment. And finally, animals are often subject to structural forces, many of which are imposed on them by humans. These all shape their narrative, and we are able to respond to this in ways that are dignifying or undignifying.

This may strike some as an overextension of the framework. But in fact, I think this is able to support a lot of our intuitions about the human/animal relationship. For all the foibles in the human treatment of animals, we extend a great deal of consideration to our animal companions. One place we can see this is in expenditure: the average dog caregiver spends about $1,200 a year on their charge per annum, and dry dog food alone accounts for well over five billion U.S. dollars in sales every year (data from 2020 by (Statista 2022, n.p.)). Furthermore, death with dignity is already a well-established practice when it comes to animals. And ag-gag laws, which make illegal the recording and distribution of recordings of animal abuse in the animal industries, are popular because they prevent the public from seeing the kinds of practices entailed by industrial animal agriculture that makes the average person shudder, precisely because these conditions are violations of the animals standards—of their narrative (see, for instance, Potter 2011). And animal welfare laws generally prohibit the torture of animals, even if we own them. Despite all of the ways
in which capitalism disrupts positive relationships with animals, we still see it as wrong to violate their desire for a pain-free life without due cause.

We may even be able to extend the account further, beyond animals. Biocentrism, deep ecology, ethical mysticism, and indigenous accounts of the environment emphasize the relationship between people and land as being mutual, respectful, and equal. I find it very plausible that against such a background the relational account of dignity extends to the environment, and that we can meaningfully speak of dignifying nature. Notably, the Federal Ethics Committee on Non-Human Biotechnology (ECNH) of Switzerland has worked to solidify the Swiss commitment to the dignity of all living beings. In 2008, they published an Nobel Prize winning brochure on the dignity of plants, where dignity refers to “the value of the individual organism for its own sake” (Federal Ethics Committee on Non-Human Biotechnology (ECNH) 2008, 3; also referenced in (Rosen 2018, 4)).

The Committee is clearly motivated by a universal account of dignity, but meaningfully extends this to all living things, citing various frameworks including biocentrism, ecocentrism, as well as the very idea of “diversity” (Federal Ethics Committee on Non-Human Biotechnology (ECNH) 2008, 9, 12-13). Nevertheless, this powerful declaration of the inherent value of plants demonstrates that extensionism in the case of dignity is innovative, but not unprecedented. In short, I see the potential for extensionism as an important feature of the framework. It underscores the ways in which the account is not merely suitable for clinical ethics, but has the potential to have broad applicability within applied ethics.
CHAPTER 4: Relational Dignity in Surrogate Decision-Making

A. Uncertainty and Surrogate Decision-Making

This section moves from a discussion of the role of uncertainty and autonomy in good medical decision-making to the inherent moral fraughtness of surrogate decision-making. This is an important groundwork for the following discussion, because it establishes the limits of good surrogate decision-making, insofar as this kind of decision-making is inherently imperfect. Medical decision-making often entails navigating a vast web of uncertainty: potential diagnoses, variety of treatment options and combinations, competing odds, gaps in research, established vs. new methodologies, complex patient-provider relationships, institutional bureaucracies, financial contingencies, and so on. Some of the kinds of uncertainty that exist here are contingent. For instance, a single-payer insurance scheme would take away a significant portion of the institutional and financial uncertainty. Obtaining second opinions and working with patient advocates might mitigate some of the uncertainties around diagnoses, variety of treatment options, and patient-provider relationships. Other kinds of uncertainty are not so easily mitigated. Gaps in research and new methodologies present a lack of usable data, and odds are indications of mere likelihood—one can beat the odds for better or worse. These kinds of uncertainty are inherent in these types of decisions. Good medical decision-making must recognize the different kinds of uncertainty that exist, so that contingent uncertainty can be minimized, and inherent uncertainty can be properly acknowledged and navigated.\(^\text{30}\)

In cases where the patient is incapacitated, decision-making falls onto another person. This person becomes the surrogate or the representative of the patient in the decision-making process. As this pertains to medical decisions, these cases inherit the uncertainty that is present in personal medical decision-making, both contingent and inherent. But it also introduces a different kind of uncertainty, namely that of the unknowability of other minds. We cannot, even under the most advantageous circumstances, know with absolute certainty what the right decision is for another person, if we judge this by the modal standard of what their decision would have been in this situation had they been capacitated to make it. This problem is greatly exacerbated in cases of unrepresented patients. And this is a significant problem given the centrality of patient autonomy in medical decision-making.

Patient autonomy is one of the cornerstones of Western clinical bioethics. Looking at the history of bioethics, it quickly becomes clear why. Some of the most

\(^{30}\) For a brief philosophical discussion of uncertainty in medicine, see (Tonelli and Upshur 2019).
egregious, systematic violations of human rights in recent history can easily be explicated in terms of a denial of human autonomy and the lack of informed consent. In chapter 1 we saw how a disregard of autonomy and informed consent gave rise to some of the most horrific cases of human experimentation in recorded history, and how we can trace the development of clinical bioethics as we know it today, through the responses to these devastating horrors in the form of, among others, the Nuremberg Report and the Belmont Report. Chapter 1 also demonstrated how a series of influential court cases were a key factor in shaping our modern understanding of bioethics in the United States, and how they contributed to the formal recognition of the role of the patient as an agent in medicine.

Patient autonomy has an important relationship to uncertainty. While good medical decision-making requires that contingent uncertainty be minimized as much as possible, and that inherent uncertainty is acknowledged and explored, it is through the patient’s exercise of their autonomy that this uncertainty is navigated and ultimately resolves into a decision. This resolution is of course not absolute, in that it doesn’t create certainty, but it does determine or issue in a course of action. This makes clear the importance of informed consent in relation to patient autonomy. Informed consent requires that a patient has all the information that they, as an agent, might require in order to exercise their agency autonomously. This, of course, doesn’t require that all uncertainty is eliminated. Rather, it requires that contingent uncertainty is minimized, and that all inherent and remaining uncertainty is recognized and accounted for. Uncertainty, here, is part of the set of information that validates the consent. With respect to uncertainty, it is the patient deciding autonomously in light of their being sufficiently informed about the relevant uncertainties that constitutes a good medical decision.

In cases of surrogate decision-making, the patient themselves is not acting as the agent, and so they cannot decide autonomously in this manner. This means that patient autonomy is not present in the way that is required for good medical decision-making. The direct exercise of patient autonomy could, of course, be substituted with knowledge of their agentive directives. For instance, if a decision needs to be made whether a comatose patient will be intubated, and they have an advance directive that clearly states that they do not wish to be intubated, then we can act with reasonable certainty in accordance with their wishes.

Nevertheless, cases of surrogate decision-making are rarely this straightforward, and an advance directive can often be a double-edged sword. Given the infinite variability of medical situations, it is impossible to provide an advance directive that is both usable and complete in all or even most circumstances. This is true even if we set aside common misunderstandings concerning medical treatments such as CPR. This means that, safe for the situations adequately expressed by an advance directive, it is impossible to know with certainty what the patient would decide. This means that the very act that ordinarily sanctions the
decision, namely the autonomously deciding in light of sufficient information including that concerning uncertainty, is missing. The agent does not get to resolve the uncertainty themselves.

As a result, there is no good, morally unproblematic medical decision-making in the case of an incapacitated patient. The result is always morally fraught and the best we can do is to develop frameworks for good surrogate decision-making. This is not a novel insight, as many of these frameworks exist and are regularly employed by bioethicists and physicians. Nevertheless, there is no established consensus on what this framework ought to look like. Moreover, it is often thought that an ideal framework will be able to resolve moral conflicts. As the foregoing discussions shows, this expectation is mistaken. Instead, we must recognize that the work these frameworks will do is to improve upon the process of surrogate decision-making, allow for good surrogate decision making without ultimately resolving their moral complexity and fraughtness.

In cases of surrogate decision-making, the relational account of dignity does not merely look for a substitute exercise of autonomy, but seeks to establish and interpret the patient’s narrative as carefully as possible. This includes acknowledging the ways in which their narrative is unable to accommodate autonomous decision-making. In doing so, the account is able to acknowledge the moral fraughtness of surrogate decision-making. In doing so, it emphasizes the need for uncovering the patient’s narrative and pushes back against coopting the narrative. Ultimately, this framework of relational dignity is not meant to be a decision-procedure blackbox that inputs data and spits out morally required courses of action. Rather, it is meant to be a framework from which to consider the issue of surrogate decision-making, so as to facilitate better decision-making. In other words, the purpose of this framework is to support better surrogate decision-making by clarifying structures of justification for these kinds of decisions.

### B. Relational Dignity and Surrogate Decision-Making

Surrogate decision-making poses an immediate challenge, because it strikes at the fundamental notion of patient informed consent, and is by its very nature paternalistic. As a result, ethical surrogate decision-making requires that we find methods for safeguarding what we value most in informed consent. This is not necessarily, as we'll see, a robust substitute for the agency mechanisms. Rather, it’s about making decisions that fit the person's narrative. Importantly, this is not to cast cases of surrogate decision-making as a field unto its own. Our conceptual framework should not work only in cases of surrogate decision-making, but it absolutely should work in those cases too.

In his discussion of paternalism, Luban explains that there are certain
situations that are likely to exacerbate paternalism. A strong-willed defended set on an unrealistic legal strategy toward acquittal might find that their advocate overwrites their decisions in favor of ones with a greater chance for success. However, in the case of a person who is unable to understand and take responsibility for their actions, there is the possibility of an acquittal or even avoiding standing trial at all. This means that if a person is legally incompetent, they are not put in a situation where they have to act in a manner of great legal consequence. This also means that this person avoids the severe paternalism that might be required in order to stage an adequate defense (unless, that is, pursuing the status of legal incompetency is itself paternalistic). In medicine, this situation is importantly different, as being incapacitated offers no opportunity to circumvent medical decision-making. This requires that decisions be made for the patient, rather than by the patient.

The case of Mary Beth discussed above begins to illustrate this problem. And this case is not an aberration as much as an illustration of a broader phenomenon of surrogate medical decision-making, where the threat of paternalism, and so of humiliation, is high. Recall the case Capacity for Preferences, restated below. This case came from an article by Jason Wasserman and Mark Navin entitled “Capacity for Preferences: Respecting Patients with Compromised Decision-Making” (2018). The authors use the case to urge surrogates to take into account the preferences of unrepresented patients in medical decision-making, for reasons of liberty and respect for persons (Wasserman and Navin 2018, 31).

Case—Capacity for Preferences

[The patient is a] Forty-one-year old male who at age twenty-five had been involved in a car accident that left him paralyzed from the waist down and with a traumatic brain injury ... He had a court-appointed guardian and had lived in group homes since becoming paralyzed ... He was admitted to the hospital for stage 4 decubitus ulcers on his legs resulting from lack of hygiene and refusal of wound care ... the patient consistently refused wound care ... [and] denied that he was paralyzed. [Treating physicians were considering three potential courses of action, namely] a six-week course of intravenous antibiotics [requiring] six weeks of prolonged restraint, amputation below the knee, or no curative action but comfort care in the hospital and then hospice once he became septic. (Wasserman and Navin 2018, 33, 32)

Wasserman and Navin never resolve the case in the article. They suggest that the patient did not get the opportunity to express their preference for any of the options, and it is unclear what course of action the treatment team ultimately went with. However, it is of note that they specify that “No one from the ethics consultation service seriously advocated for the third option, although it was acknowledged as
likely to be the least coercive” (Wasserman and Navin 2018, 32). The case discussion therefore makes it explicit that the treating physicians and ethics consultants engaged in undue medical paternalism with respect to this patient. Each of the other two options entail significant periods of restraint and/or rehabilitation. These are considerable demands to make of someone who is unable to recognize and affirm that they are paralyzed in the first place, and unable to care for themselves.

There are several important takeaways from the article, for instance that capacity is not an all or nothing feature of cognition, and that even if someone has been deemed incapacitated, that does not mean they necessarily become passive in their own care. The article also undermines itself in notable ways. The authors outright reject the comfort care option. The treatment team neither presents this option to the patient as part of a “bounded choice” (Wasserman and Navin 2018, 33), nor would they have felt obligated to follow through on that option had the patient expressed a stable preference (Wasserman and Navin 2018, 37). This may seem *prima facie* reasonable, but it conflicts with the article’s broader argument. The authors appeal to the values of respect for persons and liberty—core values in clinical bioethics—to argue for the moral importance of preferences. This means that the incapacitated patient should have their preferences taken into account, even when they are in some way suboptimal. Part of the justification for according preferences this weight even in the absence of capacity more generally, is that patients with capacity will sometimes make sub-optimal decisions, and that these decisions must be respected in light of the same values of respect and freedom. In this case, the team recognizes comfort care as the least invasive option. It is reasonable to understand “least invasive” as among the options that best preserve liberty and respect for persons, especially if the individual in question objects to the invasive nature of the alternative treatments. It might even be the course of action the patient is able to express a stable preference for, had they asked. And it is certainly an option a reasonable patient with capacity might choose for themselves, and one that makes sense with respect to quality-of-life considerations.

It’s worth pausing to note the degree to which the other two treatment options would violate the patient’s autonomy. The non-surgical route would require six weeks of restraints. Assuming that the patients would not ascend to this, this entails a substantial violation of bodily autonomy. Given that the patient’s mental state is unlikely to improve from what has been their baseline for over fifteen years, it is likely merely a matter of time before they return to the hospital in a similar condition. The surgical route may also require a period of restraints, post-operative care that they might refuse, and a process of rehabilitation that evidence suggests that will not complete. We should therefore not see the various treatment options as guaranteeing their intended outcome, but as likely forestalling a return to similar circumstances.
The point here is not that the freedom and autonomy of patients must never be infringed upon. Or that we can never act contrary to the patient's narrative. However, such violations must be justified in consideration of those very same values. We can think of a patient who has an infection and is refusing treatment. However, the kind of infection that they have is known to affect cognitive function. Many of this patient's narrative features indicate that they would ordinarily seek treatment for their condition. Their family and the medical team concludes that the infection is affecting their capacity. They decide that the temporary restriction of autonomy through restraints in order to administer the requisite course of antibiotics is permissible because this will likely restore the patient’s capacity for decision-making and their ability to exercise their autonomy. In this case, the surrogate decision-makers ignore considerations of dignity and autonomy and confine themselves to a purely medical best interest standard in order to reject the option of comfort care and hospice. They subsequently embrace these values in their discussion of the alternative treatment options. This process is paternalistic, inconsistent, and morally fraught. I do not argue here that the ultimate decision to treat the patient rather than offer palliative care was wrong. Rather, the wrong lies in (1) failing to take seriously one of the medically indicated options, and (2) failing to attempt to communicate with the patient about their preferences—a key narrative component. This, then, was a procedural failure that poses a high risk of undignifying the patient.

It’s worth contrasting the outcome of the above case with a notably similar case. This case occurred at the University of Tennessee Medical Center, where I was part of its deliberation.

Case—Amputation or Death

The patient is a seventy-two-year old man without known friends or family, who suffers from hypertension, diabetes mellitus, peripheral vascular disease, and schizophrenia. He has been admitted with four necrotic toes. When he was previously admitted with a similar problem on his other foot, the physician and ethics committee jointly decided on a below-the-knee amputation (BKA). The patient consented on the condition that he would be provided a prosthetic leg. It was reasonably expected that he would be able to receive this. However, he was never fitted with a prosthetic leg, likely due to effects resulting from his mental illness. Given his current condition, preventing the spread of gangrene up the foot and leg would require amputation. The degree of damage cannot be determined pre-op, which means that amputation could range from removing just the toes, all the way to an above-the-knee amputation (AKA). Alternatively, the patient could be
provided with a comfort-focused plan of care without amputation. This would likely result in sepsis and ultimately death.

Initially, given the medical facts of the situation, the committee followed the Wasserman and Navin case in leaning toward amputation. In order to substantiate a decision, however, the treatment team and ethics worked to determine as much of the patient’s narrative as possible. The patient had been withdrawn since admission, and conversations with them revealed that the patient expressed a stable preference against amputation. A consult with the staff of the nursing home where he has resided since his last BKA, reveals that the patient values his independence and resists any help with his activities of daily living. He refuses transfer by Hoyer lift, preferring to transfer himself. He is generally distrusting of others, but in particular toward medical personnel. Given his interests and preferences, the nursing home staff anticipates a much lower subjective QOL as a double amputee, as this would constitute a significant loss of autonomy and independence. It is, for instance, unlikely that he would be able to continue to independently transfer himself in and out of bed. Given this more complete account of the patient, the committee seriously considered a comfort-focused plan of care without amputation (UTMC Ethics Committee, 2018).

These two cases, *Capacity for Preferences and Amputation or Death*, both distinguish between the patient’s ability to participate in decision-making versus their ability to make decisions for themselves. Together, they demonstrate that, even if it is established that a patient lacks capacity, that doesn’t mean they should no longer be engaged or consulted with respect to their treatment. While the patient in either case lacked full decision-making capacity, they were still able to articulate some testimony, desires, and preferences. Furthermore, in the latter case, the team was able to identify key values and uncover aspects of the patient’s relationship to medical professionals and institutions. All of these elements came together to form a narrative that was instructive in coming to a dignifying decision.

It seems that in the Wasserman and Navin case, little was done to fill in the picture of who this person was, what they valued, and how this may affect the decision at hand. By contrast, the UTMC ethics committee was willing to consider a comfort care approach, and did not dismiss this out-of-hand. Taking seriously the narrative of the patient, the structure of their life that includes their testimony, desires, preferences, values, relationships, and institutional ties, might in this case mean that we must give priority to their independence and dignity over medical best interest. The different ways in which these similar cases were treated shows the importance of relational account of dignity in surrogate decision-making.\(^\text{31}\)

\(^{31}\) The discussion of these two cases has been adopted from two previous presentations, namely “Vestiges of Agency: Medical Decision-Making for Incapacitated Patients” at the Tennessee Value and Agency Conference (2019), and “According to My Ability and Judgment;’
C. Relational Dignity and Alzheimer's Disease

Alzheimer's disease is the primary cause of progressive dementia in older adults' (Mayo Clinic Staff 2021, “Dementia,” n.p.). It is a significant contributor to the need for surrogate decision-making. Alzheimer’s cases are particularly meaningful for our purposes, because, first, there is an extensive philosophical and medical literature on the subject; two, the period of onset means that it is more likely that there is some form of advance directive that may come to conflict with the person’s later assertions; three, surrogate decision-making often occurs over an extended period of time, comprising a great variety of decisions, and; three, drastic shifts in narrative can complicate surrogate decision-making. This section demonstrates the virtues of the narrative account of dignity by applying it to Alzheimer’s cases. It starts with a brief overview of the pathological nature of Alzheimer’s disease, and then discusses two major philosophical contributions on the subject, by Ronald Dworkin (1993) and Agnieszka Jaworska (2005) respectively. I subsequently discuss several Alzheimer’s cases with respect to their narrative features, before offering case analyses in terms of relational dignity.

The Nature and Consequences of Alzheimer's Disease

Alzheimer’s disease (AD) is a widely known, debilitating illness which “refers to a particular onset and course of cognitive and functional decline associated with age together with a particular neuropathology” that results in dementia (Lopez, González, and Léger 2019, 231). It was first described in 1906 by Dr. Alois Alzheimer, based on a patient encounter five years earlier (Lopez, González, and Léger 2019, 231). Aetiologically speaking, Alzheimer’s disease is caused by “Changes in amyloid precursor protein (APP) cleavage and production of the APP fragment beta-amyloid (Aβ) along with hyperphosphorylated tau protein aggregation” which in turn cause “reduction in synaptic strength, synaptic loss, and neurodegeneration” (Lopez, González, and Léger 2019, 231). Essentially, Alzheimer’s disease is caused by a mistake in protein production, which leads to a buildup of protein that causes the death of neurons in the brain. This leads to dementia, or “acquired progressive cognitive impairment sufficient to impact on activities of daily living” (Lane, Hardy, Schott 2018, 59). The degenerative nature of Alzheimer’s disease means that after onset, symptoms gradually worsen over time, causing decline in mental and physical functioning, ultimately leading to death.

Research interest into the pathology and potential treatments of the disease has been growing. PubMed shows the following results from the query “Alzheimer's
disease” (data as of 11 March 2022) in Table 2 on the next page. This growing body of research is indicative of the growing concern with Alzheimer’s disease and dementia. And this growing concern reflects the increasing commonality of Alzheimer’s disease, which “is now the most common form of neurodegenerative dementia in the United States with a disproportionate disease burden in minority populations” (Lopez, González, and Léger 2019, 231). Furthermore, an aging population is one that is increasingly vulnerable to this disease. It’s estimated that “44 million people live with dementia worldwide,” a number which is “predicted to more than triple by 2050” due to the fact that the global population is on average getting older (Lane, Hardy, and Schott 2018, 59). The race is on to better understand its cause, symptoms, and to develop a cure.32

The COVID-19 pandemic has brought additional urgency to Alzheimer’s Disease research. COVID-19 interacts with Alzheimer’s Disease in a variety of direct and indirect ways. One clear instance is the effect of isolation on people with Alzheimer’s Disease, which “has a deleterious impact on uninfected AD patients and inhibits AD prevention” (Hardan et al. 2021, 8). More directly, “AD has been identified

32 It’s worth drawing brief attention to the FDA approval of Aducanumab (brand name: Aduhelm) on June 7, 2021. Aduhelm gained high levels of attention prior to its release as it was “Hailed as the first drug with the potential to modify the course of [Alzheimer’s] disease’s pathology” and was “Designed to slow disease progression” (Spichak 2021, n.p.). It works by “targeting and removing amyloid plaques in the brain,” that is, it attempts to remove the neuron-killing buildup of protein (Mayo Clinic Staff 2021, “Alzheimer’s Treatment,” n.p.). The approval of Aduhelm has been controversial. It was “approved under the accelerated approval pathway,” which is not on its own unusual and merely “requires the company to verify clinical benefit in a post-approval trial” (US. Food & Drug Administration 2021, n.p.). However, the committee that reviewed the drug was not informed that the accelerated approval pathway was being considered” and “a post-approval confirmatory trial will not be completed until 2030” (Tampi, Forester, and Agronin 2021, n.p., citing Alexander and Karlawish 2021). Moreover, the FDA’s own committee “recommended strongly against approval,” as they had found that “studies failed to prove the medicine works, or that its benefits outweigh side effects, which include swelling and bleeding in the brain” (Powell 2021, n.p., emphasis added). This means that, in a rare move, the FDA approved aducanumab against the recommendation of its own panel of experts (Powell 2021, n.p.), and members of the panel “resigned in protest” (Lasek 2022, n.p.). There are also other potential issues with the drug, including questionable efficacy and high costs (Tampi, Forester, and Agronin 2021, n.p., citing Alexander and Karlawish 2021). The approval of Aduhelm was sufficiently contentious that it “has sparked investigations both in the US House and at the Department of Health and Human Services” and “Two large healthcare systems in the United States (Cleveland Clinic and New York’s Mount Sinai Health System) … decided not to carry aducanumab in their formulary” (Tampi, Forester, and Agronin 2021, n.p.). And on February 10, 2022, news hit that “Biogen [is] hit with a class-action lawsuit involving Alzheimer’s drug Aduhelm” for securities fraud (Lasek 2022, n.p.). “The complaint alleges that Biogen had effectively abandoned the drug, but that the company switched course following closed-door meetings with the FDA, announcing that it would apply for approval based on a new interpretation of older clinical trial data” Lasek 2022, n.p.).
### Table 2: PubMed Results for “Alzheimer’s Disease”

<table>
<thead>
<tr>
<th>Time Period</th>
<th># of Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>The period from 1913-1940</td>
<td>5</td>
</tr>
<tr>
<td>The period from 1941-1950</td>
<td>38</td>
</tr>
<tr>
<td>The period from 1951-1960</td>
<td>151</td>
</tr>
<tr>
<td>The period from 1961-1970</td>
<td>124</td>
</tr>
<tr>
<td>The period from 1971-1980</td>
<td>465</td>
</tr>
<tr>
<td>The period from 1981-1990</td>
<td>7,127</td>
</tr>
<tr>
<td>The period from 1991-2000</td>
<td>22,777</td>
</tr>
<tr>
<td>The period from 2001-2010</td>
<td>45,228</td>
</tr>
<tr>
<td>The period from 2011-2020</td>
<td>90,693</td>
</tr>
<tr>
<td>The year 2021</td>
<td>15,805</td>
</tr>
<tr>
<td>The year 2022 (extrapolated)</td>
<td>18,860</td>
</tr>
</tbody>
</table>
as one of COVID-19’s most common CNS [Central Nervous System] comorbidities” (Hardan et al. 2021, 8). Additionally, “several studies have documented cognitive impairment in COVID-19 patients” of the kind that may suggest increased odds of developing Alzheimer’s disease after COVID-19 infection (Hardan et al. 2021, 7). While “there is currently a lack of acceptable data to substantiate this association,” this should nevertheless be investigated in future studies (Hardan et al. 2021, 7).

In many ways, then, Alzheimer’s disease is one of the major problems of our time, and it intersects with many other problems, including global pandemic responsiveness, rising healthcare cost, an aging population, and so on. It also presents unique challenges in the context of medical decision-making. One particular manifestation of this, is cases wherein a person with Alzheimer’s disease recorded their medical wishes in an advance directive while fully capacitated, but seems to have a substantial change in opinion after disease has progressed. The following sections look at two major views from the relevant literature, namely Ronald Dworkin’s discussion of Alzheimer’s disease and autonomy from his Life’s Dominion (1993) and Agnieszka Jaworska discussion of the same in her “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value” (2005). The subsequent sections will offer a response to both Dworkin and Jaworska from the perspective developed over the course of this project.

Ronald Dworkin’s “Life Past Reason”

In his Life’s Dominion, Dworkin discusses a number of philosophical issues that have death at their center (1993). His concluding chapter, “Life Past Reason,” concerns the very issues that are central in this chapter, namely the nature of dignity and its relation to surrogate decision-making for those with (advanced) Alzheimer’s disease. The main question at the Dworkin is interested in, is whether Alzheimer’s patients have autonomy, such that this autonomy must be respected in their contemporaneous decision-making regarding their care.

Dworkin’s expressed focus is on patients with late-stage Alzheimer’s disease, whom on his description “have lost substantially all memory of their earlier lives and cannot, except periodically and in only a fragmented way, recognize or respond to other people, even those to whom they were formally close” (Dworkin 1993, 218). And while these patients may be able to express desires, “these change rapidly and often show very little continuity even over periods of days or hours” (Dworkin 1993, 218). In light of this, Dworkin asks if there is “some minimum level of mental competence essential to having any rights at all?” (Dworkin 1993, 219). In other words, what is required for dignity? For autonomy? Answering this question will shed light on whether the advance directive or the current expressed wishes are authoritative.

An underlying question here concerns the feature of autonomy that explains why we should respect the decisions people make for themselves. Dworkin first
examines the evidentiary view, which “holds that we should respect the decisions people make for themselves ... because each person generally knows what is in his own best interests better than anyone else” (Dworkin 1993, 223). This view falls short, however, in accounting for cases of weakness of will (Dworkin 1993, 223). That is, we generally don’t think we should stop people from pursuing harmful actions if they decide on them freely. Perhaps people would be more productive if they were only allotted 60 minutes of video streaming time per day, and many people would love to limit their Netflix consumption to an hour a day. But we don’t think it’s anyone’s business to actually limit our access in such a manner. A similar point holds, in particular in the medical literature, for dignity of risk. While there are many practical and moral complications, we generally want to allow people, even those without full capacity, to be able to consent or assent to certain levels of risk, because people can reasonably decide on a risky course of action (Marsh and Kelly 2018, 297, 309). The point is that we don’t always know what is best for us, and even when we do know, we don’t always act accordingly. And unless we want to permit extreme paternalism regarding all manner of aspects of our lives, “knowing what is best for oneself” cannot be the basis of autonomy. Autonomy allows people to choose suboptimal ways of living, and so autonomy cannot (merely) be coextensive with knowing one’s own best interests (Dworkin 1993, 223-4). But if were to accept this view anyway, then the fact that Alzheimer’s disease disrupts the person’s ability to understand their own best interest means they do not possess autonomy (Dworkin 1993, 226).

Next, Dworkin investigates the integrity view, on which autonomy “derives from the capacity it protects [namely] the capacity to express one’s own character—values, commitments, conviction, and critical as well as experiential interests—in the life one leads” (Dworkin 1993, 224). Here, the question becomes one not of autonomy itself, but about the capacity to live a life according to one’s character (Dworkin 1993, 224-5). Dworkin argues that Alzheimer’s disruption of the person’s capacities and character is so severe that this is not possible, and so they do not possess autonomy (Dworkin 1993, 226).

Dworkin maintains that the person must be respected as a person, but the question is what does this look like in this situation, and what does this mean for decision-making. Dignity, Dworkin holds, is about self-respect (Dworkin 1993, 221). But without the ability to comprehend one’s own place in their life, it is difficult to see what self-respect would amount to in this situation. Dworkin notes that late-stage Alzheimer’s patient’s “have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self … because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole” (Dworkin 1993, 230).

He argues that decisions are authoritative when they are made in a capacitiated manner. Therefore, to respect a person is to make decisions based on what they expressed in a capacitated manner. In this case, this would be what the
individual stated in their advance directive. This is what Dworkin calls “precedent autonomy” (Dworkin 1993, 226, italics removed). Dworkin likens surrogate decision-making in scenarios like this to how a fiduciary is supposed to act in the interest of the entity they represent (Dworkin 1993, 229). On this analogy, the fully capacitor person charges their surrogate with securing their interests in the future.

Throughout this chapter, Dworkin emphasizes the distinction between experiential interests and critical interests. Experiential interests refers to the interest we have in the quality of distinct experience, like pleasure (Dworkin 1993, 201). This includes judgments about what we enjoy. These interests can change over time, and they are inherently subjective. For instance, as a child I didn't like coffee, but I do now. I wasn’t then, nor am I now, wrong about my experience of coffee. Nor am I wrong about enjoying coffee, even if my doctor says I should abstain.

Dworkin defines critical interests as those which make “a life successful rather than unsuccessful” (Dworkin 1993, 200-1). In a way, these act like Kant’s hypothetical imperatives. If I have an understanding of what makes life good for me, then I can act in ways that promote, or fail to promote it. For Dworkin, these critical interests are, as the name implies, critical to our understanding of autonomy. And Alzheimer’s undermines this vital ability to act in accordance with our critical interests (Dworkin 1993, 230).

Dworkin’s treatment of this issue implies, first, that whatever critical interests an Alzheimer’s patient have don’t matter much, because they “have no contemporary opinion about their own critical interests” (Dworkin 1993, 230). Further, he suggests that whatever critical interests they might have don’t matter, because they cannot act in accordance with them (Dworkin 1993, 230). And finally, he suggests that whether these contemporary critical interests can be met is of little importance, because what matters is the patient’s “character of [their] life” on the whole, “not just its sad final stages” (Dworkin 1993, 230).

Dworkin understands dignity as “the intrinsic importance of human life” (Dworkin 1993, 236). This is a broadly Kantian, universalist understanding of dignity. He clarifies this conception of dignity by contrasting it with beneficence, noting that we can recognize the importance of life without “accepting any general positive obligation to make it go better” (Dworkin 1993, 236). For Dworkin, we ought to “mark [the patient’s] moral standing, and ... affirm the importance of the life he has lived, by insisting that nothing be done to or for him that, in our community’s vocabulary or respect, denies him dignity” (Dworkin 1993, 237). And dignity merely requires that we acknowledge their standing, not that we respond to their current requests. Instead what is required, is that we respond appropriately to the character of their lives. And character is most developed when they are capacitated—that is, when they are able to live according to their critical interests (Dworkin 1993, 237).

In order to understand how Dworkin’s analysis works in practice, we can look at one of the cases he discusses.

127
Case—Mary in the Dark

Often, Mary was afraid, a nameless shapeless fear. … People came, memories came, and then they slipped away. She could not tell what was reality and what was memory of things past. … The tub was a mystery. From day to day she could not remember how to manage the water: sometimes it all ran away, sometimes it kept rising and rising so that she could not stop it. … Mary was glad when her family came to visit. Sometimes she remembered their names, more often she did not. … She liked it best when they just held her and loved her. (Dworkin 1993, 220, quoting Mace and Rabins 2012, 1-4).

According to Dworkin, Mary has no real grasp on her life. She may have experiential interests, insofar as she likes to be held and loved by her family, but she is unable to acquire or even substantiate critical interests. This means that she lacks autonomy, and respecting Mary’s dignity is limited to respecting her as a person. We are not required to consult Mary or take into account her desires when making decisions for her. Moreover, respecting Mary’s character, taken over the course of her life, means honoring whatever decisions she made when she was capacitor, even if it appears she no longer values those commitments.

Agnieszka Jaworska’s “Respecting the Margins of Agency”

In “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value,” Jaworska offers a competing account of the relation between autonomy and Alzheimer’s disease. While she does not focus on dignity as much as Dworkin does, the way she develops her account of autonomy in terms of an individual’s abilities to desire, value, and express preferences lines up well with the relational account set out in this project. One case in particular is central in Jaworska’s discussion, so it’s worth presenting it here once more in its full length:

Case—Mrs. Rogoff’s Change of Heart?

Mrs. Rogoff was always an independent woman. Raised in an immigrant family, she was used to working hard for what she wanted. Most of her life she ran a successful business selling liquor. She also developed local fame as an outstanding cook and hostess. After her third husband’s death she lived alone, enjoying what she considered, by old-country standards, a luxurious lifestyle: keeping up a nice big house and indulging in restful leisure. She was an introvert, always carefully guarding the way she presented herself to others. Life interested her insofar as she could live according to her own sense of
comfort, making her own mistakes and relying on her own strength and wisdom.

In her early eighties Mrs. Rogoff developed severe motor impairments, which could only be corrected by a risky neurosurgery. She decided to undergo the procedure, insisting that she would rather die than be immobile. She prepared a living will, requesting not to have her life prolonged if she became a burden to her family or if she could no longer enjoy her current quality of life.

The surgery was successful, but shortly thereafter Mrs. Rogoff developed early signs of dementia: memory and word-finding difficulties. As she became more and more disoriented, her daughter hired a housekeeper, Fran, who moved in with Mrs. Rogoff. Fran takes care of Mrs. Rogoff the way one would take care of a child. Mrs. Rogoff enjoys the long hours she spends with Fran, and with her grandchildren whenever they visit, telling them somewhat disjointed stories about her earlier ventures. She watches TV a lot and her stories often incorporate the more exciting episodes from TV as if they pertained to her own life. In her more lucid moments, Mrs. Rogoff tells her grandchildren that she is scared to die, that “she doesn’t want to go anywhere.” She usually cries when Fran is away and when her grandchildren wrap up their visits.

Fran has to make day-to-day decisions for Mrs. Rogoff: Should Mrs. Rogoff get dressed if her family is coming to visit and she insists on wearing pajamas? Should she take a bath every day even if she is afraid of water? Should she be taken to fix her dentures, if every excursion out of the house makes her scared and unhappy? In general, should the current decisions reflect the care Mrs. Rogoff used to take in how she presented herself to others? Mrs. Rogoff’s daughter faces the more weighty decisions: Should she use up Mrs. Rogoff’s savings to pay Fran’s salary, allowing Mrs. Rogoff to keep enjoying her companion, or should she place Mrs. Rogoff in a nursing home, increasing the likelihood that, when the time comes, there will be some money left to execute Mrs. Rogoff’s will? What treatments should she authorize if Mrs. Rogoff develops a dangerous but treatable infection? (Jaworska 2005, 105-106).

This decision was made in the context of a complicated medical procedure, so it’s not clear what Mrs. Rogoff had in mind when completing the advance directive. Perhaps she imagined a much different complication from the surgery. And it’s not clear what it would mean for Mrs. Rogoff to be a burden to her family. And what are the relevant features of quality of life? Did she mean to set her pre-surgery QOL as the absolute baseline, or did she mean “a life about as enjoyable as mine is currently.” Setting this ambiguity aside, Jaworska is responding in particular to two competing
accounts on how to navigate surrogate decision-making for Alzheimer’s patients. One of these views is that of Dworkin, as set out in the previous section. The other is that of Rebecca Dresser, as set out in her “Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law.” Dresser straightforwardly holds that “The legal standards governing decisions on life-sustaining treatment for incompetent patients should be revised. The present reliance on patients’ past preferences and on imputed reasonable person values fails to reflect true concern for incompetent patients, for it assigns priority to values and desires that can no longer matter to the patients themselves. Decisions ought to be guided by systematic assessments of incompetent patients' contemporaneous interests” (Dresser 1986, 404).

Jaworska tries to carve out an space that takes “seriously the current interests of demented patients,” but not because it fails to show concerns for the patients the way Dresser suggests (Jaworska 2005, 109). Rather, argues that by reconceptualizing autonomy, we can understand Alzheimer’s patients as being able to exercise autonomy in (morally) relevant ways. This means that her account contrasts quite fundamentally with that of Dworkin.

Jaworska locates the crux of Dworkin’s argument in “the assumption that dented patients no longer originate critical interests” (Jaworska 2005, 112). This is a significant claim, and one that not clearly holds up, not even within the confines of Dworkin’s cases. Recall Dworkin’s case of Mary who wanted to be held and loved (Dworkin 1993, 220). It is clear that there are experiential interests at play here, namely an interest in physical contact, and in affection. But to say that these are disconnected from or void of critical interests seems mistaken. Is this kind of affection not a good to many of us? Perhaps the average person has a better, more complete understanding of their preference for affection and how this fits into their lives, but that doesn’t mean that the lack of such an understanding undermines the role of such affection in one’s life. As Jaworska states: “dementia causes a person to lose some of her earlier more complex interests, so that in the new, simpler configuration the remaining interests gain import” (Jaworska 2005, 112). The average person may value a plethora of things, and have a rich set of critical interests each of which can fluctuate in its priority and strength. This means that this person can be missing out on some of the elements that comprise their ideal life while still living a good life. For the Alzheimer’s patient, there may be but very few elements that contribute good to their life. And so these elements become ever more critically important.

Central to Jaworska’s account is her understanding of what it means to have values. She argues that to value requires that “the person thinks she is correct in wanting what she wants; achieving what she wants is tied up with her sense of self-worth; and the importance of achieving what she wants is, for her, independent of her own experience” (Jaworska 116). She concludes that “Nothing here suggests
that valuing would require a grasp of the narrative of one's whole life" (116). This is to push back on Dworkin's central claim, that it is precisely the lack of this grasp that undermines autonomy. Of course, the fact that a grasp on the narrative isn't necessary doesn't mean the narrative itself is missing.

Jaworska's account requires that Alzheimer's patients are capable of valuing, rather than the mere expression of desires. She convincingly supports this with a number of cases, among them the following.

Case—The Value of Useful Work

Dr. B. was an Alzheimer's patient who scored low on cognitive tests and "could not recall the day of the week, the month, or the year." He was unable to "evaluate his life as a whole," but he nevertheless "proved capable of valuing." He became involved in a research study by Dr. Sabat on Alzheimer's disease, and grew interested in the study itself. While he could not understand the study in detail, he thought his participation meant he was engaging in something important. "He told Sabat more or less explicitly that he considered the project right and appropriate: 'And you know I feel a way is that, I feel that this is a real good, big project, and I'm sure you do too. This project is a sort of scientific thing.'" Participation in the project meant that Dr. B. was doing more than the "filler" projects that occupied his time at the adult day-care center. "If I'm working with you, I can—look, I can work in here for 30 times and all that, but in this group, I'm nothing." It is clear that participation in the project has a significant effect on Dr. B's perception of himself (Jaworska 2005, 118, original emphasis, citing Sabat 1998)

Jaworska notes that the very fact "That his role in the project could so alter his self-image demonstrates most poignantly that he valued the project" (Jaworska 2005, 118-9). While Dr. B. has trouble recalling the basic temporal features that are relevant to his life, and who cannot locate himself in his own life's story, he nevertheless took great pride in his involvement in the research project. He saw this as much more meaningful and fulfilling than the "filler activities" he would otherwise have to engage in. Dr. B's conviction is stable over time and has the relevant accompanying desires, participation in the study is tied up with his self-worth, and independent of his experiential interests. That is, participation may be challenging and confusing, but is still worthwhile. We can say, therefore, that Dr. B. legitimately values participating in the study.

Dworkin infers from the Alzheimer's patient's inability to meet their goals independently, that they are unable to set their goals independently. And this underpins his claim that Alzheimer's patients lack autonomy, which ultimately means that the advance directive is authoritative even if it contradicts presently
expressed desires. Jaworska, by contrast, distinguishes between the ability to set goals and meet goals, noting that “the essence of the capacity for autonomy consists in the ability to lay down the principles that will govern one’s actions, and not in the ability to devise and carry out the means and plans for following these principles” (Jaworska 2005, 128-9).

The fully autonomous person of course does have both capacities. Autonomy is about the capacity to value, and deciding and acting in accordance with those values. Requiring assistance in acting out a decision based on a sincerely held value does not negate the presence of autonomy. To illustrate, consider the following case.

Case—Going Out Tonight?

Mrs. Johnson, who is quadriplegic, is considering attending an event that evening, namely a talk by their favorite author. She was planning on going, and arranged for the necessary assistance to get ready and make it to the venue and back. However, she received a message from her son, asking if he could come visit. If Mrs. Johnson were to decide against attending the event, then she will not require the necessary assistance to leave her house. If she decides to attend, then she will require assistance to follow through on this decision. Mrs. Johnson values both the author and the opportunity to attend a talk by them, as well as spending quality time with her son. Either decision, then, would be in line with her values. But going out requires assistance, while staying in does not.

Dworkin’s analysis would force us to conclude that to stay in would be for Mrs. Johnson to be autonomous, while to go out would be for her not to be autonomous. This borders on the confluations of two senses of autonomy: namely moral autonomy and practical autonomy. Here, moral autonomy is the ability to value and live in accordance with one’s values, whereas practical autonomy is the ability to do so independently. What is important to see is that we can have moral autonomy without practical autonomy. All of us need assistance with some things in our lives, and some of us need more assistance than others. The idea that every limit on our practical ability is a limit on our moral autonomy is both dangerous and unfounded.

Jaworska pushes back against Dworkin’s analysis, noting that “a principle suitable as a basis of self-governance must be viewed by the person as correct for her” (Jaworska 2005, 129). It’s worth for a moment to reflect on this notion of self-governance. To govern is to conduct affairs with authority (Oxford Languages n.d., n.p.). And so to self-govern is to conduct one’s own affairs with authority. But in neither the general sense nor the self-direct sense does “conduct” require full independence—and it rarely if ever does. It merely requires one to participate in the management of the relevant affair (Marriam-Webster n.d., n.p.). Thus,
self-government requires one to participate in the management of one's affair with authority.

It's clear that Mrs. Johnson and Dr. B. both meet the requirements for self-governance, *whether or not* they can enact their value-based decisions without any assistance. So Mrs. Johnson and Dr. B. do possess autonomy. Jaworska recognizes that “Full-blown autonomy involves not only acting on one's own principles and convictions, but also the ability to scrutinize these principles and to revise them in light of critical evaluations” and of course this capacity may well be missing for the Alzheimer’s patient (Jaworska 2005, 130). Nevertheless, “the capacity to value by itself does, in a very important sense, render a person capable of autonomy” (Jaworska 130). And indeed, “given the help … they all can live up to their own ideals again, and to that extent exercise autonomy” (Jaworska 2005, 131).

Killmister makes a relevant observation with respect to dignity and the need for assistance, and in particular “The connection between embodiment and personal dignity violations” (Killmister 2020a, 46). She cites the *indifference* that can be constitutive of such violations, in particular in healthcare, where patients are frequently “denied the means to uphold those norms” (Killmister 2020a, 47, original emphasis). She cites the case of Marry Duffy, whose doctor exposed her to “a half-dozen medical students” while she was “half-asleep on the morning after her breast cancer surgery” without so much as acknowledging her (Killmister 2020a, 46, quoting Carey 2005). Both Killmister and Jaworska emphasize the important notion that dignifying people requires care, attention, and understanding. It requires proper uptake.

What the conflicting conclusions regarding Mrs. Johnson’s case demonstrates is Jaworska’s points that “once a demented patient is recognized as a valuer, the problems are not, in principle, different from those encountered when working with ordinary competent people (Jaworska 2005, 135). That is, people encounter problems of practical reason all the time, especially in a medical context. But these difficulties do not erase them as current participants in decision-making.

This conceptualization of autonomy connects beautifully to the way narrative has been developed in this project. On this account of autonomy, what is minimally required for autonomy is the capacity to value. What relational dignity in the context of surrogate decision-making requires is that we take up with these values in how we understand and respond to the person. This is, after all, one of the functions of surrogate decision-making, i.e. “to originate the appropriate bases for one's decisions that can then be, if the need arises, partly taken over by others” (Jaworska 2005, 134). What is vital, is Jaworska’s recognition that “If a demented patient remains a valuer, her contemporaneous interests and her contemporaneous autonomy have full moral standing” (Jaworska 2005, 135).
Alzheimer's Disease and the Disjointed Narrative

Dworkin and Jaworska’s account different radically, both in their approaches and ultimate recommendations, which underscores the importance of developing an accurate and practicable framework for surrogate decision-making. One thing that is notable is the differences in cases that each author cites. Dworkin’s cases are generally bleak, and paint a picture of Alzheimer’s patients’ lives as full of fear and paranoia, or otherwise sad and empty. He emphasizes these features even where the cases don’t necessarily reflect this. In support of his grim interpretation of Alzheimer’s cases, Dworkin cites cases from Nancy L. Mace and Peter V. Rabin’s *The 36-Hour Day* (2006/1981), which he calls “chilling” (Dworkin 1993, 220). It is notable that the authors themselves describe the attitudes of Alzheimer’s patients as variable. Some “become depressed or irritable” while others “remain outwardly cheerful” (Mace and Rabins 2006, 7). Moreover, they recognize that, in particular “the person with a mild to moderate dementia is able to continue to do most of the things he has always done” including “participate in his treatment, family decision, and planning for the future” (Mace and Rabins 2006, 7). Even when they are confused, they should “have a part in deciding things as much as possible,” while remaining careful not to “overload the person’s decision-making ability” (Mace and Rabins 2006, 25, 37). In light of this, it is also noteworthy that while Dworkin supposedly limits himself to late-stage Alzheimer’s (Dworkin 1993, 219), Jaworska rightfully challenges this, noting that his application concerns “patients who are, or at least could be, in earlier stages of dementia” (Jaworska 2005, 135). Jaworska’s analysis supports the idea that there can be different outcomes for different people, even in very similar circumstances. A sensitivity to the details of a case is very important, because it’s these details that make the narrative unique to the person.

A further feature that stands out about Dworkin’s account, is that he’s trying to provide a singular answer to the question about advance directives. Jaworska paints a more nuanced picture, a broader spectrum of cases from fear to general contentment, to full-fledged happiness. Dworkin’s cases prime our intuitions make his argument more compelling. The conclusion that we should disregard the current preferences of Alzheimer’s patients against an extant advance directive requires that we discount their current status.

There are some other potential problems with Dworkin’s account. For one, he clarifies his conception of dignity by contrasting it with beneficence, noting that we can recognize the importance of life without “accepting any general positive obligation to make it go better” (Dworkin 1993, 236). Interestingly, he makes the case for this claim in reference to the U.S. criminal justice system, wherein prisoners must be treated with dignity (having the value of their life acknowledged, and not be murdered or tortured) without actively having their lives improved (Dworkin 1993,
Dworkin explicitly notes that incarceration here is motivated by deterrence and isolation from society (Dworkin 1993, 236).

This analogy is at the very least unfortunate, if not telling, because this understanding of the criminal justice system is highly criticized. The United States system of retributive justice results in the routine dehumanization of its subjects, including violations of human rights through extended solitary confinement, and the continuation and exacerbation of racial inequality through the criminal justice system (see, for instance, Alexander 2010; Vasiliades 2005). While the analogy is meant to show how the recognition of the value of life comes apart from positive duties potentially related to this duty, it moves beyond Dworkin’s point to demonstrate the dangers of making and enforcing this distinction. Restorative justice, by contrast, is about realizing the promises of autonomy by making good on the relevant positive duties (see, for instance, Ward and Langlands 2008; Van Ness 2013). Here, incarceration becomes about rehabilitation, and about supporting individuals in creating and accomplishing their critical interests. The distinction between dignity and beneficence as Dworkin paints it is not an inherent feature of the criminal justice system. It is extraneous, often lapses into dignity-undermining treatment, and is enforced through violence. The analogy therefore draws into question whether or not this distinction between dignity and beneficence can be sustained in the case of vast power differentials, which would have consequences for attempting to enforce this distinction in the case of Alzheimer’s patients.

There is a book by the Dutch author J. Bernlef entitled *Hersenschimmen* (2011/1984). The novel is about Maarten Klein, a Dutch immigrant living in the United States, who is diagnosed with dementia. Written from the first-person perspective, the reader experiences Maarten’s decline through a narrative that starts out clear and structured, but becomes increasingly disjointed and confused. The book has been translated to English under the title *Out of Mind* (1989), but the Dutch more literally translates to brain-specter or mind-shade. This seems like a trivial difference, but the difference in connotation is, I think, quite meaningful. “Out of mind” implies an absence of mindedness, and suggests that one has left behind reason and perhaps even thought all together. This interpretation, then, signals a view of dementia that lines up with Dworkin’s analysis. The original title more accurately represents the change in consciousness. It’s not that one’s mind is gone, but the clarity and definition have given way to opacity and silhouette—which are not negligible narrative qualities.

One of the challenges in evoking “narrative” in any kind of account of ethics or identity, is that the term functions at least in part as a metaphor. It’s meant to point to a kind of thing that exists about a person. Their testimony. Their story. Their account, description, or history. *Something like that*. This is why it’s vital to specify what precisely it is we mean by “narrative.” While Dworkin doesn’t mention “narrative” explicitly, his account makes it clear that he would not ascribe narrative to
the dementia patients whose cases he describes. And insofar as narrative implies things like, cohesion, chronology, detail, and so on, this seems like a reasonable conclusion. What Bernlef’s novel demonstrates very nicely, is that the Alzheimer’s patient does still have a narrative. Because the book is written from a first-person perspective chronicling the outlook of someone who suffers from dementia. It is by definition a narrative. And it may be increasingly disjointed and uncertain, but this does not change its fundamental nature as that of a narrative. And as such, it provides grounds for dignifying action and decisions.

Notably, Jaworska repeatedly uses the term “narrative” to refer to the fractured elements of the Alzheimer’s patient’s life, and so her usage is somewhat ambiguous with respect to the persistence of narrative. However, she uses the term as more synonymous with “story,” with the coherent and linear relationship between past and present, where the latter is similarly coherently projected into the future. We often think of narrative like this the way Husserl thinks of retentational consciousness, where a recent experience is retained in short-term memory, current experience are interpreted against this background, while simultaneously creating a protection, or anticipation, for the future (Boenn 2009, n.p.). This model has already been applied to the phenomenology of music and to a lesser degree the analysis of narrative. We retain the past and make sense of the present against this backdrop while simultaneously creating an anticipation for the future.\footnote{For a more elaborate discussion of time-consciousness in Husserl and more recent phenomenologists, see (Gallagher 2017).}

And while this is precisely how narrative often works, disjointed narratives are still narratives, albeit with its phrases less expressive, and its connections less clear.

One feature that is central to our humanity, and one which is often forgotten when we consider advance directives and surrogate decision-making, is that values change. And this especially true when being confronted with radical change. A near-death experience may inspire someone to quit their dreary job and go after their dreams. Being dealt a temporary bad hand in health or finances might make one more compassionate towards others. And becoming a parent can shift one’s focus away from their professional development toward their home life.

I remember a conversation I had with a friend a couple of years ago, when we were both early graduate students. We were talking about mental decline, and I expressed that if I were to lose my rational capacities, I wouldn’t want to keep on living. My self-image was very deeply wrapped up with my life in academia and my career aspirations. This shifted radically after having children, just 2 years later. Now, as long as I can enjoy the company of my family, I think I’d be very happy.

Losing part of one’s cognitive capacity, as in the case of Alzheimer’s disease, is to lose a part of ourselves that is central in how most people navigate their lives. In that sense, it’s not only a personal loss, but a social one. It’s acute and world
shattering. If we can understand value-shifts caused by near-death-experiences, the deaths of close relatives or friends, making it through a hard time, meeting a significant other, having children, and so on, surely we can appreciate value-shifts that are the result of such a significant loss. The key point here, though, is to understand this as a (radical) change in values, rather than the complete dissipation of values.

Dresser’s analysis is centered on the idea that the current Alzheimer’s patient is no longer the same person as whomever completed the advance directive. On her account, Alzheimer’s disease is sufficiently disruptive to cause a break in the continuity of a person, without causing the total degeneration of personhood. This claim is made against the background of the personal identity literature. Indeed, when we consider Alzheimer’s cases through the lens of analytic philosophy concerning personal identity, the first question we must ask is whether this is still the same person that recorded their wishes. If so, then the question becomes whether the disease is undermining their decision-making capacity. Given the effects of Alzheimer’s on decision-making relevant features, in particular short-term and long-term memory, the answer is likely to be “no.”

Since Alzheimer’s doesn’t merely disrupt a person’s memory, but can almost entirely severe a person’s mental continuity. It can also cause significant changes in personality. This may lead us to conclude that this is no longer the same person. The question then becomes, to which person do we have fidelity? We may think that it is the former person who had their wishes recorded. This is Dworkin’s position. He argues that “If I decide, when I am competent, that it would be best for me not to remain alive in a seriously and permanently demented state, then a fiduciary could contradict me only by exercising an unacceptable form of moral paternalism” (Dworkin 1993, 231, emphasis added).

Alternatively, we can think that we have fidelity to this new person. The problem is that they do not have decision-making capacity, which raises the question of how to decide for them. Here, we can reasonably conclude that given the unique connection between the person who had their wishes recorded and the person presently in front of us, we should use the advance directive as our guide in decision-making. So regardless of whether we think this person is the same, we have a lot of reason to think that the advance directive we have access to is binding. Framing the issue in terms of relational dignity causes a significant shift in how we approach this situation. The question is no longer about whether this is the same person, but about the person’s narrative.

We could ask a parallel question to the one above, and wonder which narrative we should have fidelity to. But considering the past narrative over the one that is currently in front of us really only makes sense if we can reasonably see a return to that narrative. We saw the importance of this feature in the Cowart case as well. And because we have no reason to think that Mrs. Rogoff’s narrative will realign with the
one that produced her advance directive, it's unclear why that narrative should be authoritative. Instead, the framework suggests we work to read and interpret the current narrative. And there is a lot of evidence that can help us do this, that is, all the narrative features we can extract from the case, including stable preferences over time, contented behavior during family visits, testimony during lucid moments, etc. From what we know about Mrs. Rogoff now, her narrative, and what the people closest to her support, is that she is living a life that she is happy to live and happy to continue living, even if this requires medical assistance.

Relational Dignity Analyses of Alzheimer's Cases

Jaworska concludes that “The fact that a person is no longer competent to make decisions for herself, or that she has lost the threat of her life as a whole, does not imply that her advance directive is automatically authoritative in guiding what should happen to her. So long as the person is still a valuer, current decisions on her behalf ought to take seriously her current values” (Jaworska 2005, 137). The account I have provided in this project embraces this conclusion and works to expand on its central element. While not understating the importance of values and the capacity for valuing, this is but one element of what makes up the structure of a person's life. A key difference between Jaworska's analysis and mine, is that hers is concerned with the limits of autonomy. It is clear from the foregoing that between dignity and autonomy, the latter is the more narrow concept. We can have dignity without autonomy. There are cases where we can meaningfully speak of narrative and dignity even in the absence of autonomy. We can see this by developing Mrs. Rogoff's case in terms of some of the central features of narrative.

Expressed Elements of Narrative

- Testimony: Mrs. Rogoff expresses that “she doesn't want to go anywhere.”
- Actions: Mrs. Rogoff “enjoys the long hours she spends with Fran, and with her grandchildren.”
- Behaviors: Mrs. Rogoff “cries when Fran is away and when her grandchildren wrap up their visits.”
  (Jaworska 2005, 106)

Personal Elements of Narrative

- Attitudes: Mrs. Rogoff generally has approbative attitudes toward Fran, her grandchildren, and her favorite programs on TV.
- Desires: Mrs. Rogoff's desires appear to correlate with her values (below).
- Values: Mrs. Rogoff values time spent with Fran, her grandchildren, and watching her stories on TV.
- Preferences: Mrs. Rogoff appears to have a stable preference for living her life.
- Understanding: There is a general lack of understanding on the part of Mrs. Rogoff, though in her more lucid moments she iterates her desire to be alive (Jaworska 2005, 106).

Social Elements of Narrative
- It seems that while many of Mr. Rogoff's relationships have eddied away or shifted, she maintains important relationships with her care provider, Fran, and her grandchildren.

Structural Elements of Narrative
- There are many structural issues that relate to this case, but perhaps the most important one, certainly in this context, is the need to balance the Dworkian consensus view with the implications of both Jaworska's discussion as well as this project. That is, we must acknowledge the fact that the consensus view is broadly accepted, and that this may bias decision-making in favor of the advance directive. This creates an obligation to resist this bias, and to more carefully evaluate the narrative features of this case.

The relationship between autonomy and values is clear, but the way our values become realized or actionable through the exercise of our autonomy is enhanced and constrained by a myriad of factors. "Valuing" is therefore itself quite narrow. Narrative, as the underpinnings of relational dignity, provides a more expansive and complete account of the relevant features to surrogate decision-making, especially if we're interested in dignity sans autonomy. Relational dignity grounded in narrative therefore provides a most complete safeguarding of the dignity of the patient in surrogate decision-making.
Chapter 5: Challenging the Traditional Case Format

Clinical ethics often proceeds by the process of discussing case studies. These case studies emerge from two distinct conventions, namely the use of cases and thought experiments in philosophy, and the medical case format in medicine, which is influenced by chart note customs. One issue that I have so far not explicitly addressed is how or by what method a practitioner is going to be able to weigh what’s most important among the various parts of a narrative. Here, a crucial start is how a clinician is able to recognize and identify the relevant features of a person’s narrative. A good first step in this process is rethinking the traditional case format. This chapter presents cases in their traditional and extended format and discusses their difference with respect to the narrative-based account of relational dignity.

A. Relational Dignity through Narrative Cases

A Literary Case

In “Showing that Medical Ethics Cases Can Miss the Point: Rewriting Short Stories as Cases” (2018), Woods Nash uses Richard Selzer’s short story “Fetishes” (1999), to extract a case in the traditional format. He develops the case as follows.

Case—The Denture Dispute, Part 1

Audrey, a 57-year-old woman, consents to a total hysterectomy after a 10-cm cyst, which might not be benign, is found on her right ovary. Admitted to the hospital the day before surgery, Audrey speaks with the anesthesiologist. He tells her that she cannot retain her upper denture during the procedure because it presents added risks. Nor, he tells her, may she reinsert it until she is fully awake. She explains that she has had the denture for fifteen years and does not wish for her husband, who is unaware of it, to see her without it when he visits her soon after the operation. It is a matter of her “dignity,” she says. Unmoved, the anesthesiologist reiterates that she cannot keep it in, and he leaves. Later that evening … Audrey considers refusing the operation and leaving the hospital. (Verbatim from Nash 2018, 192)

Most analyses of the initial presentation of the case will generally support the anesthesiologist’s insistence on the removal of the patient’s dentures. This is basic

---

34 Nash explains that “Fetish’ often refers to a sexual fascination with something," however, in the context of this story, it refers to a more general “excessive commitment or a charmed and revered object” (Nash 2018, 195).
medical best practices, and it seems unwarranted to violate this standard based on the patient’s desire for keeping in their dentures.

Case—The Denture Dispute, Part 2

[A]s Audrey considers refusing the operation and leaving the hospital, she is visited by Dr. Bhimjee, a surgical intern assigned to her case. She tells him of her dilemma: the anesthesiologist’s instructions versus her wish that her husband not see her without the denture. Dr. Bhimjee promises to reinsert her denture during recovery, before she is fully awake. The operation proceeds as planned, and Dr. Bhimjee keeps his promise. Audrey is wearing the denture when her husband visits and tells her that the cyst was benign. (Verbatim from Nash 2018, 192)

If we’re evaluating Dr. Bhimjee’s approach we are likely to conclude that it was supererogatory. This still leaves us with a lot of questions. We might wonder why Dr. Bhimjee assisted the patient in their request, why did the patient invoke dignity here, and what did she mean by dignity in this context? While the traditional case presentation does not give us the equipment to answer these questions, the story itself does contain the necessary information. The abridged version of Nash’s extensive discussion of the story follows (quoted from Nash 2018, 196-200; paginated citations in block quote are original and in reference to Selzer 1999).

Case—The Denture Dispute (Extended)

And there is Leonard. Audrey had waited until she was thirty-two to marry. Not by choice; no one had asked her. But all the time she had never given up hope, so that when Leonard Blakeslee had come along, she had at once reached out her hands for him as though he were an exotic foreign dish whose very strangeness captured her appetite completely. “You’ll love me?” she asked him, and never once in all these years had he given her reason to doubt it. The fact that no children had come along was briefly regretted by both of them, then accepted. Somehow, it suited them.

... When Audrey was forty-two, she saw a dentist. Discovering her rotten upper teeth, he treated her with derision and accusation: “Pyorrhea, the dentist had said. Said it severely. ‘You’ve let it go. They are all rotten and ready to fall out on their own.’ Audrey was flabbergasted. ‘I have to think,’ she had said. ‘My husband isn’t here. He’s in New Guinea’; and then she wishes aloud that Leonard were present to help her make the right treatment decision (99). In response, the dentist seems to mock Audrey’s indecisiveness and dependence
on her husband. … Audrey opts for full extraction and a denture with ivory-colored false teeth. … “She hadn’t been out of the dentist’s office ten minutes when she knew that she had made a dreadful mistake.” Wondering “what Leonard would think” and “how he would feel” about her new appearance, Audrey worries that she may have thrown away her “dignity.” Believing her worth to be bound up with her value in her husband’s eyes, and not wanting to risk his disapproval, “then and there Audrey decided that Leonard didn’t have to know” (99). Her dignity can still be salvaged. For the two months before Leonard returns, Audrey practices speaking with the denture inserted and even keeps it in while sleeping. She only removes it for cleaning. Soon, she has “incorporated” it and doesn’t mind it at all (99). In fact, the denture comes to mean more to her than its standard functions would suggest. It is a fetish: “The denture had become for her a kind of emblem of personal dignity … this having to do with the one thing that mattered most to Audrey: Leonard” (100).

Fifteen years pass, and Audrey finds herself a patient again. This time, she is in a surgeon’s office. For a cyst on her right ovary, the surgeon insists on a total hysterectomy. “A clean sweep,” he exclaims—as if she were nothing but a kitchen floor, Audrey thinks (100). And he goes on to explain that she does not “need her reproductive organs anymore, that the risk of getting cancer in one of those organs was ‘not inconsiderable.’” Audrey is aghast: “Human beings do not talk like that, she thought. That is not human speech.” Knowing already what it is like “to go through life missing something” (100), Audrey is reluctant to consent to a total hysterectomy: “Only my ovary, the one with the cyst. Nothing else, unless there is cancer” (101).

Like her denture, Audrey’s reproductive system—despite its infertility—stands for something more: “her womanhood, yes, it was nothing short of that” (100). … He presses on until she capitulates and signs the consent form: “You’re doing the right thing, I assure you, Mrs. Blakeslee” (101).

When Audrey is admitted to the hospital the evening before surgery … [the anesthesiologist enters]. “I’m Dr. Dowling.’ The man had knocked and come in at the same time. It is what happens in hospitals, she thought” (101). … [A]nd his commanding knock is a harbinger of the ease and power he ascribes to his every action and instruction. “Open your mouth wide [sic] as you can.’ He peered in. ‘I see you have an upper plate. Out it comes in the morning before you leave this room!’” (102). Audrey begins to protest, to explain that she never removes it. “Mute shadows of words trembled at her lips” (102). But the anesthesiologist will not listen. In stark contrast with the story’s early description of Audrey’s denture as “incorporated” (99), the anesthesiologist is
insensitive to its status: “I cannot put you to sleep with a foreign body in your mouth.’ Foreign body! Audrey felt the blood leave her head. Gongs could not have sounded louder in her ears” (102).

Audrey tries again. She pleads, explaining that “it is important” to her that Leonard not see her without her denture (102). But like the dentist years ago, the anesthesiologist only belittles and accuses: “‘Pride,’ said the man. ‘No room for it here. Like modesty.’” He continues: “‘Suppose we had to get at your trachea, your windpipe, in a hurry, and then we had to waste time fishing those teeth out. Suppose they came loose in the middle of the operation. There are a hundred “supposes.”’ He started to go,” convinced that his words had settled the issue. Audrey retorts that it isn’t pride: “It’s dignity,” she tells him (102). But once again, his reply is condescending: “You are making too much of it” (103). … “Audrey felt her heart go small in her chest … “ (103). She starts seriously considering leaving the hospital.

…

“Almost at once there was a hesitant knock at the door”—a knock so unlike the anesthesiologist’s (105). “‘My name is Dr. Bhimjee. I am the intern on this ward.’ … ‘Mrs. Blakeslee, I see that our names both end with two e’s,” he says (105). … All at once, a fence came down. Who, after all, is to say where, in whom, one places trust? ‘I have false teeth,’” she says, “shocked at the ease with which the forbidden words had come.” “Many people do,” the intern calmly responds. … She tells Dr. Bhimjee of the secret she has kept from her husband and of the anesthesiologist’s instructions, and she pleads with him for another way. “For a long moment they looked at each other, during which something, a covenant perhaps, Audrey did not know, was exchanged” (105). He assures her not to worry and promises to take her false teeth with him to the operating room. “Before you leave the recovery room, I will put them back into your mouth. Do not worry” (106). Dr. Bhimjee keeps his promise. Audrey’s denture is in place when Leonard visits and tells her the cyst was benign. (Nash 2018, 196-200)

The way Audrey uses dignity actually fits very well with the conception of dignity I have developed in this project. It is not that in encountering her husband without her dentures her fundamental human value is undermined, or that the moral status of the anesthesiologist’s insisting on the removal of the dentures is decided by reference to Audrey’s universal dignity.

Expressed Elements of Narrative

● Testimony: Audrey expresses that she wants to keep her dentures in, and moreover, that she does not want her husband to see her without dentures. She claims this undermines her dignity.
• Behavior: Audrey has a visceral response to being told she cannot keep her dentures in.
• Actions: Audrey considers foregoing an important surgery in order to avoid having to take out her dentures for an extended period of time.
• Embodiment: Audrey’s dentures are an important part of how she exists and relates to the world.

Personal Elements of Narrative
• Attitudes: Audrey has a strong disapprobative attitude toward taking out her dentures.
• Desires: Audrey strongly desires to keep her dentures in, even if this poses a risk to her health.
• Values: Audrey values the way she presents herself to the world, and in particular her husband. Her dentures play a significant role in how she conceives of this presentation.
• Preferences: Audrey has a stable preference for keeping her dentures in and, with respect to her husband, maintaining the illusion of having natural teeth. Since she considers leaving the hospital when this appears to be impossible, we can reasonably conclude that this preference is incredibly strong.
• Understanding: Audrey appears to understand the relevant information.
• (Medical) History: Audrey’s history with the dentist makes her hesitant about engaging with medical professionals.

Social Elements of Narrative
• Audrey values her dentures not merely as part of her self-image, but as a symbol of her relationship with her husband.

Structural Elements of Narrative
• Audrey has been treated in a way that she believes is indicative of the medical field, with derision and pedantically.

The dentures represent an essential component of Audrey’s narrative, in terms of her testimony, her actions, behaviors, and embodiment, her preferences and values, and her relationships to her husband. Each of these elements captures the vital role of Audrey’s dentures in her narrative. This entails that the actions of the anesthesiologist were undignifying—potentially humiliating. The anesthesiologist was altogether uninterested in hearing Audrey’s testimony, in taking up with her testimony, and understanding her values. They lacked the attitude that is requisite for the narrative-based account of relational dignity to take hold. Dr. Bhimjee, by contrast, enters into the situation with a radically different attitude. They are willing
to hear Audrey, to listen, interpret, and understand. And they are able to dignify Audrey by responding appropriately to her narrative.

**Rethinking *(How) Do We Choose Our End?***

I want to conclude by reconsidering a case that has been central to this project, namely *(How) Do We Choose Our End?* We have already seen two iterations of this case, i.e. the basic version and the expanded version. I represent the basic version first, and subsequently discuss the case in a more casual, narrative-driven way, before evaluating the differences these distinct case formats entail.

**Case—*(How) Do We Choose Our End?***

The patient is a 46 year old female patient. She came in “feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. They did a bone-marrow biopsy and she was diagnosed with acute myelomonocytic leukemia. The oncologist proposed a course of induction chemotherapy, followed by consolidation chemotherapy, and finally a bone-marrow transplant. The survival rate of this course of treatment is about 25%. The survival rate of no treatment is about 0%. The oncologist met with the patient to inform her of the diagnosis and had made plans to begin induction chemotherapy that afternoon. This enraged the patient, who refused treatment. When the patient saw their treating physician several days later, they remained steadfast in their refusal for treatment, with limited support from their family. A couple of weeks later, the patient came to the physician requesting barbiturates to aid in sleep. While barbiturates can be a powerful sleep aid, their non-prescription use can also result in death. In conversation with the patient is becomes clear that they are planning to use it as a sleep aid, but that they are also aware of its secondary use, and wish to have enough of the medication to be able to commit suicide. By law, the physician is banned from providing assistance in patient suicide. The physician must choose whether or not to assist the patient. (Originally from Quill 1991a)

To see how this framework of relation dignity might affect our approach in a medical decision-making context, let’s look once more at the details of this case, originally presented by Timothy Quill in “My Patient’s Suicide” (1991a). This time it is presented in a longer, more narrative format.

Diane was feeling tired and had a rash. Her hematocrit was 22, and her white-cell count was 4.3 with some metamyelocytes and unusual white cells. I
called Diane and told her it might be serious. When she pressed for the possibilities, I reluctantly opened the door to leukemia. Hearing the word seemed to make it exist. “Oh, shit!” she said. “Don’t tell me that.” I thought, I wish I didn’t have to. (Quill 1991a, 32)

Already this story has taken a radically different form from the case presented above. It’s clear that the physician, Dr. Quill, and patient know one another, that their conversation is relatively casual. That Quill knows Diane by her name. He knows her as a vaginal cancer survivor, someone who has struggled with depression, who is nearly four years sober, a business owner and artist, and has over the last few years deepened her relationships with friends and family.

Quill researched her options at length, and found that a series of chemotherapy treatment would ultimately give her a 25% at survival, whereas abstaining from treatment would mean “certain death in days, weeks, or months” (Quill 32). The situation was so severe that the oncologist had planned on starting chemotherapy the same afternoon that they informed Diane of the diagnosis. Diane, however, was enraged at his presumption that she would want treatment and devastated by the finality of the diagnosis” (Quill 1991a, 32). In the following days, it became clear that Diane understood her options, the risks and benefits, and was steadfast in her decision to not undergo treatment. Her family wished she would choose treatment but accepted her decision” (Quill 1991a, 32).

Over time, it became clear that Diane did not want to “linger,” but wanted to “maintain her dignity during the time remaining to her” and “When this was no longer possible, she clearly wanted to die” (Quill 1991a, 32). At Quill’s direction, Diane researched her options via the Hemlock Society, and soon requested a prescription for barbiturates to aid with sleep. When Quill meets with Diane, it was clear that she could use a sleep aid, but that she also wanted “the security of having enough barbiturates available to commit suicide, if and when the time came,” because this “would give her the peace of mind she needed to live fully in the present” (Quill 1991a 33).

I made sure that she knew how to use the barbiturates for sleep, and how to use them to commit suicide. We agreed to meet regularly, and she promised to meet with me before taking her life. I wrote the prescriptions with an uneasy feeling about the boundaries I was exploring—spiritual, legal, professional, and personal. Yet I also felt strongly that I was making it possible for her to get the most out of the time she had left. (Quill 1991a, 33)

Several months later, after regular meetings with Quill and quality time with her family and friend, Diane was declining rapidly. They met, and Diane said she “was sad and frightened to be leaving but … even more terrified to stay and suffer” (Quill 1991a,
She died two days later. Her son and husband had “no doubts about the course she had chosen, or about their cooperation” (Quill 1991a, 33).

Writing in the 90s, Quill notes that “Although I truly believe that the family and I gave her the best care possible … I am not sure the law, society, or the medical profession would agree … [Diane] taught me about life, death, and honesty; and that I can take small risks for people I really know and care about” (Quill 1991a, 34). The final sentence is particularly meaningful, as it captures and emphasizes the nature of the relationship between Quill and Diane. Their relationship was deep and meaningful. Sometimes we take these characteristics to be antithetical to professionalism and professional relationships, but this is mistaken. One of the key characteristics of a good professional is that they understand their client, their perspective and needs. In many professional contexts this perspective can be fairly limited. But when it comes to long-term health care and end-of-life care, the deeper the knowledge and understanding are, the better the care can be.

We can also analyze this in terms of the narrative features previously laid out. Diane consistently expresses a capacitated expression of the desire to control the end of her life, which coheres with her other actions and behaviors. These expressions are also consistent with her personal preference and desire to avoid excess suffering at the end of life, and this is coherent with her other values. And the decision is based on a good understanding of the relevant facts. Diane enjoys social support in her decision, from family and friends, as well as her health care provider, with whom she has had a long-standing relationship. There is a potentially a lot we can say about the structural elements of the case, but I think it suffices to stay that Diane lives a country where active euthanasia will not be available, and so her options with respect to the end of life are limited to the assistance her prescribing physician is able to provide and comfort care. Given what we know about Diane and her situation, her narrative, we can judge that Quill’s decision to support Diane in her end-of-life wishes was dignifying.

When we look at all of these factors, we can now potentially judge that Quill’s decision was dignifying. The factors that weigh most heavily in favor of this conclusion are also the ones that are least visible in the traditional case format. It is for this reason that, in making practicable the narrative-based account of relational dignity, we must reconsider our mode of case presentation.

B. Reconsidering the Case Format

The case (How) Do We Choose Our Death? has been presented in two radically different ways. We may wonder whether this change in presentation does not do more to explain the different outcomes, rather than the framework itself? Here, I draw from Woods Nash’s discussion in “Showing that Medical Ethics Cases Can Miss
the Point” (2018). Nash discusses ethics cases as a distinct genre that emphasize “action over setting ... [and] characterization” (Nash 2018, 190, citing Chambers 1997; Chambers 1999). Ethics cases will describe patients who came in, presenting with or experiencing symptoms. They undergo tests, and are subsequently diagnosed with a disease. They are then treated. This presentation of information minimizes the narrative features of the case, often erasing the “longer, non-clinical periods” (Nash 2018, 191).

Central to this conversation is the notion that “style is not neutral” (Nash 2018, 203). The case format is meant to clarify, but it can obscure a lot of information that may in fact be relevant to the situation. Analyzing the case in terms of relational dignity means that we need a narrative, and this becomes about revealing. This is also the contrast with universal dignity. Whatever facts are relevant to universal dignity don’t really change from case to narrative. But if we think the narrative-elements are important, then we need an account of dignity that is sensitive to those narrative-facts. The proposed account not only offers that sensitivity, but centralizes precisely those narrative features.

The ethics case format has been heavily influenced by the medical case format, which focuses on medically relevant information presented as concisely as possible. Thai is necessary, because charts move through many different hands, and every medical professional that comes into contact with the patient needs to be able to read up on their history quickly. However, in any medical center there are many times more medical cases than there are ethics cases. This means that, once a case gets to ethics, it has already ceased to be a standard case. This suggests that the standard case format may be inadequate in conveying the necessary information.

As we have seen, in the ordinary case, the patient as agent plays a more straightforward role in navigating uncertainty and decision-making. That is not to say that the framework developed here is of no use in the more standard cases. Much of what the relational model recommends and demands can be relevant here, as it can help direct patient-provider interactions, clarify informed consent, formulate health goals, and so on. This is in line with the direction we have seen develop in medicine over the last century, where the patient role in their healthcare has become increasingly more active and agentive.

That said, it is in especially challenging circumstances that the relational view is particularly helpful in ensuring that these standards are met. One of the ways it can help us do so is by pushing to expand what we see as necessary and relevant patient information. Ultimately, clinical ethics cases are not just philosophical thought experiments and they are not ordinary medical cases. They have uniquely challenging features that require those involved to better understand the structure

---

35 Nash’s discussion is particularly appropriate, because the case he cites Richard Selzer’s “Fetishes,” specifically concerns the issue of the nature of dignity (Nash 2018, 193-4, 199, citing Selzer 1987).
of the patient's life. This means we have to move beyond the “basic” facts that tend to be the baseline in traditional clinical ethics cases. This also helps to clarify and underscore the distinct function ethics consultancy has in medicine, as experts in navigating the moral complexities of medical decision-making.
Conclusion

I have argued that traditional ways of conceiving of dignity have theoretical and practical limitations. In particular, the universal account of dignity can fail to be applicable or sufficiently action guiding in the case of vulnerable populations. In light of this, I have argued in favor of a narrative-based relational account of dignity, which grounds standards for action and decision-making in a person’s narrative. I have explicated narrative in extensive yet concrete terms, and established its analytical and extensionist potential. Through case study applications, and in particular an extended evaluation of Alzheimer’s disease cases, I have demonstrated the practicability of this account. Finally, I have used the successes of the view to offer a critique of the standard case format, arguing instead for a more narrative-based presentation of cases.

One question I have encountered several times in presenting and discussing this project is one of practicality. There are various forms this concern can take, but I’ll lay out the three main kinds. First, there are constraints entailed by an emergency situation. If an unaccompanied, incapacitated patient comes into the ER without identifying information on them and decision need to be made, there is little narrative information to go on. These constraints would certainly significantly limit the degree to which the narrative-based account of dignity is applied. However, this is not a strike against the account, since situations of this kind present a challenge to applying any kind of standard beyond medical best interests. The account does motivate the necessary research to uncover as much about the patient as possible, and may balance the likelihood of unearthing this information against treatment decisions and timelines.

Second, since dignity is a social concept, a lot depends on the knowledge we have of the other person. Knowledge of other minds is imperfect at best, and we may understand this as a significant detriment to our ability to dignity others. As I explained in chapter 4, I think this concern is legitimate. However, it serves an important function in the account, forcing us to recognize the limits inherent in ethical surrogate decision-making, while also motivating us to minimize those limits.

Finally, there is the issue of time. It seems that this account requires a significant increase of time in at least two domains. The first is in discerning the patient’s narrative. The account intensifies pressure on clinicians to extricate an as complete as possible picture of the patient’s narrative. The second is in charting. In order for the narrative-based account of relational dignity to be practicable, the various parties that stand in relation to the patient all need access to the relevant information and how this has shaped and motivated decision-making. The concern—one that is bolstered by the discussion in chapter 5—is that it is difficult to convey this information in the current chart format, and that changes to this format
will be a poor fit with the current healthcare climate. This is a serious impediment in realizing this framework in practice. It is difficult to speculate on this issue in the abstract, as it requires concrete experience in a healthcare setting in order to evaluate options for addressing it. So there is a sense of which the next phase has to take place in a clinical context. It is therefore my aim to take up this problem in such a setting post-PhD.
References


Carey, Benedict. 2005. In the Hospital, a Degrading Shift from Person to Patient.


https://cbhd.org/about-cbhd

https://cbhd.org/content/human-dignity-fundamental-concept-bioethics


https://www.cdc.gov/tuskegee/timeline.htm


Natanson v. Kline, 186 Kan. 393 (Supreme Court of Kansas 1960).


169


Rubin, Andrea. 2018. Personal Communication between Andrea Rubin and Monica L. Gerrek. Department of Bioethics, Case Western Reserve University School of Medicine. (March 1). Cleveland, OH. Cited in (Gerrek 2018).


*Schitt’s Creek*, created by Dan Levy and Eugene Levy, CBC Television, 2015-2020.

Schloendorff v. New York Hospital, 105 N.E. 92, 93 (Court of Appeals of N.Y. 1914).


170


https://www.ushmm.org/collections/bibliography/people-with-disabilities


UTMC Ethics Committee. 2018. Amputation or Death. Notes from bimonthly meeting by the University of Tennessee Medical Center Ethics Committee, Knoxville, TN. August 28.


https://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1045&context=auilr


Vita

Born and raised in the Netherlands, Jeffrey Pannekoek first visited the United States as part of an exchange year. In 2008 he permanently moved to the U.S. and attended Utah Valley University in Orem, UT. After he completed his Bachelor of Science degree in Philosophy, he spent two years in Fort Collins, CO completing graduate level coursework. He subsequently attended the University of Tennessee, Knoxville to pursue a Ph.D. in Philosophy. During his time at UT he became interested in clinical ethics, and his research focuses on the nature of dignity and surrogate decision-making. After graduation, he will start as a Fellow in Advanced Bioethics at the Cleveland Clinic. Jeffrey is grateful for all of the support and encouragement he has received from his mentors, friends, and family.