The Ethics of Advance Care Planning

Ciaran Folliard Rhys
Loyola University of Chicago Graduate School

Follow this and additional works at: https://ecommons.luc.edu/luc_diss

Part of the Philosophy of Science Commons

Recommended Citation
Rhys, Ciaran Folliard, "The Ethics of Advance Care Planning" (2023). Dissertations. 4065.
https://ecommons.luc.edu/luc_diss/4065

This Dissertation is brought to you for free and open access by the Theses and Dissertations at Loyola eCommons. It has been accepted for inclusion in Dissertations by an authorized administrator of Loyola eCommons. For more information, please contact ecommons@luc.edu.
LOYOLA UNIVERSITY CHICAGO

THE ETHICS OF ADVANCE CARE PLANNING

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN PHILOSOPHY

BY
CIARAN FOLLIARD RHYS

CHICAGO, IL

AUGUST 2023
ACKNOWLEDGEMENTS

I would like to thank my director, Jennifer Parks, for her support and encouragement over the course of writing this dissertation. As challenging as it was to write through the COVID-19 pandemic, her expertise and consideration helped me develop an approach to theorizing about justice and care which I look forward to engaging beyond the scope of this project. I am continually inspired by her commitment to keeping systematic oppression related to age, race, and gender within the scope of philosophical analysis, and honored to receive guidance from a philosopher whose work ensures that care workers and their charges receive the recognition they deserve. I would also like to thank my committee members, Dr. Mark Waymack and Dr. Joseph Vukov, for their thoughtful questions and intriguing extensions of the ideas I’ve presented throughout this dissertation. I am certain the narratives and conjectures they have shared will occupy my thoughts as I continue my work in bioethics.

Many thanks to my teaching mentor, Dr. Jacqueline Scott, for allowing me to practice and aspire to introducing students to philosophical ethics in profound, meaningful ways. If teaching philosophy is among the te, I am grateful to have followed alongside her pedagogical practice of a tao which never loses sight of real people and real lives. Dr. David Schweickart’s seminar in existentialist philosophy provided valuable opportunities to consider intersections of theory and practice; particularly given the existential threat of climate crisis. I would also like to thank Dr. David Ozar, for an inclusive introduction to the Institutional Ethics Committee, and for his dedication to an ideal of institutional functioning which has been a beneficial counterpoint to my
comparative cynicism. Dr. Clint Moore also provided a phenomenal example of how a philosophical education can be wielded to protect patients who deserve support in their struggle to navigate the health care system. I thank all four for sharing their career paths during my years at Loyola, and hope to eventually show what philosophy can do in the world as well as each of you has shown me.

To my grandmother, Helen Krull née Folliard, whose wry sense of humor kept up my ‘minimal’ spirits during bleaker years of my life. To my mother, Gwendolyn, who is perhaps most responsible for an invaluable early introduction to reading, writing, and skillful argumentation. To my father, Carleton, for encouraging a healthy skepticism of institutions and the confidence to be deliberately gauche should the situation demand it (aside from influencing me to end sentences with prepositions in a Chicagoan way). To my siblings, Colin and Caitlin Krull, for their kind words about the value of this dissertation and their thoughtful input on the legal and medical ramifications of my work in philosophical bioethics. And to my Reese and Krull extended family, especially cousins Dylan Krull and Bryn Smith, for connecting with me over the years and helping to make my life feel less strange.

Finally, to my dearest orange cat, Dr. Michael Patrick O’Heron. Thank you for holding on to a better version of me when I have struggled, for your support as I have negotiated an inevitably shifting web of expectations and needs, and for your continual faith in my doctoral and professional trajectory. I know I could not be here without you, and I hope you are more confident in your heart and intellectual spirit every time you compassionately listen to me start a sentence with ‘I’. May we continue to exchange shared moral sentiments, collaborate on practical projects in an existentialist spirit, and continue to share everything which makes life meaningful in the years to come.
PREFACE

Advance care planning (ACP) is defined by the National Hospice and Palliative Care Organization as “making decisions about the healthcare you would want to receive if you’re facing a medical crisis.”¹ This can include obtaining information regarding treatment, making decisions about which treatments you would or would not want if diagnosed with a serious illness, communicating your values to loved ones, and completing advance directives such as a living will or power of attorney for health care.² Before the COVID-19 pandemic, only about 1 in 3 adults in the U.S. had completed an advance directive.³ More recent studies suggest that even people with chronic conditions were not motivated by the pandemic to discuss end of life care preferences with their loved ones.⁴

Yet, the COVID-19 pandemic represents the most significant decrease in global life expectancy since World War Two.⁵ The American healthcare system was already overstrained, and when hundreds of thousands more people flooded emergency rooms, it prompted the

---


² Ibid.


application of crisis standards of care. More than a million people have died from the virus,\(^6\) with older adults faring the worst. Although Americans older than 85 make up only 2% of the population, they accounted for 30% of COVID deaths.\(^7\) While there remains some skepticism about the value of end of life care planning in the health care system today, it would nevertheless have saved many people from dying alone in institutions.

My work in a hospital as a patient safety sitter was part of my initial motivation to focus on advance care planning in my dissertation. Patient sitters are often contract employees with little to no job protections or benefits, and we care for a wide variety of patients: from people on suicide watch, to people experiencing adverse medication reactions or other temporary psychological impairments. Most often, we are responsible for people with dementia who are not necessarily aware they are in the hospital. I was often dismayed by the level of treatment acuity to which my older patients seemed to be subjected. With perhaps not much longer to live, it seemed cruel to me to keep them intubated and sometimes chemically or physically restrained—sometimes for weeks or months at a time.

Although, at the same time, I questioned whether there would be comparable support to help them stand, walk, or even just sit up and have a drink of water if they were discharged to a nursing home. Most seemed not to have family members who could care for them at home or more formal home care providers. Many did not have orders for treatment limitations, and it seemed that neither families nor doctors wanted to raise the question of their appropriateness. Meanwhile, it was widely acknowledged among the nursing staff that it would be far preferable

---

\(^6\) [https://covid.cdc.gov/covid-data-tracker/#datatracker-home](https://covid.cdc.gov/covid-data-tracker/#datatracker-home)

\(^7\) Powell, Tia, Bellin, Eran, and Amy R. Erlich. “Older Adults and Covid-19: The Most Vulnerable, the Hardest Hit,” 61.
to have a “nice coronary” rather than coping with dementia on top of multiple intersecting diseases, injuries, and a relational network who does not want to admit you may be dying. The potential benefits of imagining these possibilities and talking through your preferences with your loved ones seemed salient to me then and now. I grant that communication can go awry, that it is emotionally difficult to consider one’s own demise, that people do not necessarily trust the health care system, and I acknowledge that the fragmented nature of the system is also a barrier to ACP. But these challenges should serve as motivation to reconfigure and standardize a more efficacious approach. Left unchecked, our inability to think through good end of life care will subject thousands more to cruel, intolerable deaths which could have been prevented.

The first Chapter of this dissertation, “Advance Care Planning and the COVID-19 Pandemic: A Dysfunctional Infrastructure Magnified” begins by considering whether the pandemic motivated people to consider and share their end of life care preferences. A study from the Netherlands found evidence of such a result, while a study of older and chronically ill adults in the Chicago area found many were apathetic. In fact, those in comparatively poorer health were less concerned about contracting or dying from COVID-19. Meanwhile, the official response has tended to focus on access to technology such as ventilators rather than how to support people in their homes and local communities. There have been some calls for renewed focus on ACP amongst health care professionals since the pandemic; but of three possible approaches, none appropriately reconfigures the relationships needed for successful ACP.

The second and third Chapters are more theoretical in nature. It would seem appropriate to attribute responsibility for conducting ACP to the community, on the grounds that forms of collaboration could be enhanced in ways that help people manage chronic and end of life care needs. I find this approach to be overconfident about forms of cooperation in various social
collectives. Communities are structured as much by exploitation as they are by cooperation, and lack of recognition persists in ways which harm older adults and the low wage workers who care for them. I consider a libertarian alternative proposed by Tristram Engelhardt, and although I find his account of how authority can be manufactured persuasive, his notions of identity formation and community dynamics are underdeveloped. Thus, I turn to a socio-politically oriented theory of agency proposed by Kathryn Abrams, and discuss the ways marginalized agents can form alliances and challenge oppressive master narratives. The latter is what Hilde Lindemann’s theory of counterstories aims to accomplish, and I suggest these engagements would be of value to care workers and their charges alike.

Chapter three, “Agency, Obligation, and Autonomy”, focuses on what obligations various entities have toward people in decline. The first section considers Agnieszka Jaworska’s argument that the care and value-based inclinations of people with marginalized autonomy should still warrant deference. While I appreciate the respect Jaworska extends to marginalized agents, I find Hilde Lindemann is right to counterargue that sometimes we have the duty to persuade loved ones to take actions in the service of their wellbeing, or to take measures that will minimize their suffering—perhaps especially when we know they are impaired. This engagement is what Lindemann refers to as the morally valuable process of “identity work”, undertaken by friends, loved ones and family members. Also in this Chapter, I consider Atul Gawande’s suggestions that medicine has a greater responsibility for people’s general wellbeing, and that public health and medicine should collaborate more closely. While medical and public health institutions have a lesser responsibility to promote public health initiatives, I do not find they are responsible for persuading specific persons of the value of their participation. Furthermore, overzealous practitioners and institutions can cause needless suffering when they violate patient
confidentiality and privacy more generally. The final section of this Chapter accepts Quill Kukla’s suggestion that autonomy should be understood as a set of ongoing practices that involves legitimate placements of trust in medical authorities, but turns to Barbara Ehrenreich’s socioeconomic critique of medicine to elaborate upon what kinds of acknowledgements should build trust with practitioners.

“[T]he single biggest problem in communication is the illusion that it has taken place” is a quotation widely misattributed to the playwright George Bernard Shaw⁸ which also captures the reason why efforts at ACP have been historically unsuccessful. Chapter four examines various barriers to the successful practice of ACP, including the divide between clinical practice and advance directive law, patient and surrogate hesitancy, inconsistency of care, and medical resistance to planning for end of life. These are all legitimate obstacles, but it is important to acknowledge them so that they can be mitigated. Among key reasons systems of ACP have failed is that no role of health care practitioner is ultimately responsible for conducting it, a problem I return to in Chapter seven.

Chapter five makes the case for the value of ACP, and relies on Hilde Lindemann’s account of holding to advocate in favor of it. For Lindemann, each person is “held” in their identity by others, groups, and ultimately by their own perspective on significant interactions. Friends, loved ones, and relatives perform the deeper identity work that makes us who we are, and they can be responsible for holding us in our personhood when we are in decline. The medical system, on the other hand, tends to hold on to the “life” of each person as one case among many. This tendency, along with role-related bias among physicians in favor of treatment, often entails that older adults who go to the emergency department when they face a crisis will

---

⁸ https://quoteinvestigator.com/2014/08/31/illusion/
be admitted to the hospital and then forced to defend their preferences when they are already not well. Planning who to involve in a crisis and how they should respond would save many older, chronically ill adults from this fate. Thus, I argue that the health care system has a responsibility to practice what I call “boundaried agentic holding": which is different from the kind of identity work surrogate decision makers engage in, and the holding on to life more typical of the health care system.

However, successful ACP is not merely a question of identifying who might be among a dying persons’ alliances and making sure treatment limitations are indicated on the relevant forms. Phenomena such as what Hilde Lindemann calls “infiltrated consciousness” can prevent people from thinking through their own interests and desires, and cause them to defer to others or courses of action which are not aligned with their agency. Chapter six traces the dying process of Françoise de Beauvoir, Simone de Beauvoir’s mother, in the early sixties. Although Françoise is dying of bowel cancer, she is not told of this by her physicians, who subject her to painful and humiliating procedures during her last days. As much as it might seem that Simone de Beauvoir would have a role-related duty to persuade her mother against these treatments, bringing her home to die would most likely traumatize her more than trying to hold her in her flawed values through the dying process. Thus, in considering whether Françoise ought to be persuaded or allowed to continue according to her preferences, we are forced to consider how much she stands to suffer if her daughters contravene her wishes.

The final Chapter of this dissertation provides my answer to who should be responsible for ACP: direct care workers or DCWs. DCW’s practice gives them enhanced insight into the kinds of considerations that make chronically ill and dying people’s lives meaningful, and they must navigate the boundary between over treatment and neglect in their every interaction with
their clients. Although they are some of the most disenfranchised health care providers, retraining as ACP facilitators would help them advance professionally, gain additional compensation, and be engaged in a less physically demanding type of work. Following Eva Kittay’s theory of connection based equality, I propose that employing care workers as care planners allows them to repurpose their skills in ways which help them meet their own needs, and which would contribute to healthier dependency relationships throughout society.

ACP is not a panacea for the exploitation and abuse DCWs and their charges must navigate in a society that does not attribute them much worth, but it would allow these groups to collaborate in ways that better serve their own interests and agency. With support and recognition from the hospital system, more people could avoid intolerable, medicalized deaths in institutions, while others could be connected with the services needed to make their last days tolerable and perhaps even meaningful. Care workers could be better compensated for repurposing what are both practical and moral aptitudes. While the possibility of an “easy” death may still elude us, the likelihood of an appropriate death ought not to.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>xiii</td>
<td>Acknowledgements</td>
<td>iii</td>
</tr>
<tr>
<td>v</td>
<td>Preface</td>
<td>v</td>
</tr>
<tr>
<td>xv</td>
<td>Abstract</td>
<td>xv</td>
</tr>
<tr>
<td>1</td>
<td>Chapter One: Advance Care Planning and the COVID-19 Pandemic: A Dysfunctional Infrastructure Magnified</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Could the Pandemic be a Tipping Point for the Importance of ACP? Results from the Netherlands and from the American Midwest</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>COVID-19 in the U.S.: An Exacerbation of Existing Injustice and the Increased Elusiveness of Appropriate Death</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Aspirational Approaches to ACP in the U.S. in Response to the COVID-19 Pandemic</td>
<td>22</td>
</tr>
<tr>
<td>32</td>
<td>Chapter Two: Context for Autonomy: Communitarianism, Individualism, and Agency</td>
<td>32</td>
</tr>
<tr>
<td>35</td>
<td>A Communitarian Approach to Autonomy</td>
<td>35</td>
</tr>
<tr>
<td>51</td>
<td>Liberal Autonomy Vs. Political Agency</td>
<td>51</td>
</tr>
<tr>
<td>56</td>
<td>Agency and Narrative Repair</td>
<td>56</td>
</tr>
<tr>
<td>64</td>
<td>Chapter Three: Agency, Obligation, and Autonomy</td>
<td>64</td>
</tr>
<tr>
<td>65</td>
<td>What is Owed to Those Who Cannot Care for Themselves: Compromised Autonomy and the Duty to Persuade</td>
<td>65</td>
</tr>
<tr>
<td>76</td>
<td>Threats to Agency in Context: What is Required of Health Care Institutions and Public Health Agencies</td>
<td>76</td>
</tr>
<tr>
<td>87</td>
<td>Trust and the Displacement of Individual Medical Decision-Making</td>
<td>87</td>
</tr>
<tr>
<td>94</td>
<td>Chapter Four: Historical Failures of ACP</td>
<td>94</td>
</tr>
<tr>
<td>95</td>
<td>The Divide Between Advance Directive Law and Clinical Practice</td>
<td>95</td>
</tr>
<tr>
<td>101</td>
<td>Barriers to Successful Advance Care Planning: Patient and Surrogate Hesitancy and Inconsistency of Care</td>
<td>101</td>
</tr>
<tr>
<td>108</td>
<td>The Persistence of Medicine’s Resistance to Planning for End-of-Life</td>
<td>108</td>
</tr>
<tr>
<td>121</td>
<td>Chapter Five: Why Practice ACP: A Case for Holding</td>
<td>121</td>
</tr>
<tr>
<td>123</td>
<td>Lindemann’s Concept of Holding</td>
<td>123</td>
</tr>
<tr>
<td>131</td>
<td>A Dilemma in End of Life Care: Edmund and Charlie</td>
<td>131</td>
</tr>
<tr>
<td>135</td>
<td>Holding on to Life in the Health Care System</td>
<td>135</td>
</tr>
<tr>
<td>143</td>
<td>An Alternative Approach: Respecting Choices</td>
<td>143</td>
</tr>
<tr>
<td>152</td>
<td>Chapter Six: A Very Easy Death: Recognition and Letting Go at End of Life</td>
<td>152</td>
</tr>
</tbody>
</table>
Other Operations in Identity Work: Misfiring Recognition, Letting Go, and Infiltrated Consciousness 153
A Very Easy Death? 158
The Duty to Persuade and the Appropriateness of Misshapen Response 166

CHAPTER SEVEN: CARE WORKERS AS CARE PLANNERS 171
Direct Care Workers (DCWs) and the Impact of the Pandemic on Direct Care Work 172
Why Direct Care Workers Ought to Be Involved in Advance Care Planning: A Practical Justification 180
Why Direct Care Workers Ought to Be Involved in Advance Care Planning: A Moral Justification 189

CONCLUSION 197

BIBLIOGRAPHY 201

VITA 205
ABSTRACT

The COVID-19 pandemic subjected millions of Americans to alienated deaths in institutional settings. Given that the default response to health crises is to go to the Emergency Department, isolation protocol limited the care and support ill and potentially dying people could receive at the bedside. Crisis standards of care also cut off meaningful discussions of end of life care preferences. Communication barriers regarding end of life care existed well before the pandemic, however. This dissertation proposes a new approach to the concept of Advance Care Planning (ACP), or the process of deciding what kinds of care one would prefer in a crisis or at the end of one’s life. Herein, I argue that certifying direct care workers (DCWs) to conduct ACP would expand access to this vital service, simultaneously providing these often marginalized workers with enhanced professional recognition and compensation.

Historically, doctors and nurse practitioners have been the primary professionals who could be compensated for practicing ACP, and both groups cite lack of time and preparation as reasons they avoid it. More recently ACP has garnered more attention due to the pandemic, but contemporary approaches have yet to invoke a relational configuration which will lead to it’s success. I draw from Kathryn Abrams theory of agency to argue that training DCWs to conduct ACP would enhance not just their agency, but also the agency of chronically ill and older adults. The identities of both groups are deserving of what Hilde Lindemann refers to as narrative repair. Finally, I draw from Eva Kittay’s theory of connection based equality to argue that my approach to ACP would allow DCWs to better meet their own needs and contribute to more just and equitable dependency relationships throughout society.
CHAPTER 1
ADVANCE CARE PLANNING AND THE COVID-19 PANDEMIC: A DYSFUNCTIONAL INFRASTRUCTURE MAGNIFIED

Introduction

Since it’s impetus in 2020, more than 98 million Americans have contracted COVID-19 and over a million have died from the virus.\(^1\) At the peak of the pandemic, more than 20,000 Americans were being admitted to the hospital for COVID every day.\(^2\) Of those who died, more than 80% were ages 65 and older.\(^3\) Americans older than 85 make up only 2% of the population, but account for 30% of COVID deaths.\(^4\) COVID has subjected our oldest and often most vulnerable citizens to death in alienated, tragic circumstances. Even before the pandemic, concerns about the need for advance care planning were growing: in 2019, 735 articles about advance care planning were published.\(^5\) But this concern was not necessarily mirrored by the general public, most of whom lacked advance directives or designated surrogates.\(^6\) More recently, studies suggest that even chronically ill Americans were ambivalent about the risks of

---

4. Ibid.
COVID, and avoided making any end of life care plans with their relatives and other care providers. 

The COVID-19 pandemic has significantly intensified the strain placed on an already overstrained health care system. It has subjected millions of people to a potentially traumatic institutionalization punctuated by isolation protocol and crisis standards of care. The issue that most people do not have advanced directives or surrogate decision makers is not new, nor is the problem that the default response to health crises is to go to the emergency department. But the consequences of the COVID-19 pandemic were in part avoidable: the health care system has tended to focus on technological interventions rather than communication processes that would have helped people manage decline and avoid a crisis response when possible.

This chapter begins by considering the intersecting, intolerable ways COVID-19 has subjected older and chronically ill people to unnecessary suffering and death. The health care system has ignored the realities faced by these groups for decades. I argue herein that at least some of these disastrous outcomes could have been prevented with a renewed focus on the relationships that facilitate quality of life, permit people to make decisions about their care, and avoid a crisis response if possible when critical incidents do occur. It might be hoped that the pandemic would motivate more people to consider and discuss their values about end of life with their loved ones and trusted clinicians; one study from the Netherlands did measure such an effect. There is little to no evidence of a comparable social impetus in the United States: a cross-sectional survey study of chronically ill adults in the Chicago area found that even people at high

---


risk of dying from COVID are not likely to see the virus as a threat or change their behavior. Part 1 of this chapter addresses these findings.

Older adults are most at risk, but the official response has focused on technological interventions such as ventilator access rather than supporting chronically ill people at home or in nursing homes. Part 2 of this chapter focuses on how older adults are coping at home or in institutions, and describes how barriers to care have been worsened by the pandemic. Instead of thinking through who provides care for older and chronically ill people, and finding novel ways to support the mutual agency of both parties, we have tended to either spring into crisis mode or ignore practical problems and lapse into indifference. This has exacerbated existing social injustices and made what psychiatrists such as Avery Weisman and Thomas Hackett describe as an appropriate death much more elusive.

Although there have been calls for the expansion of ACP in the U.S. response to the pandemic, these have tended not to address relational barriers which existed well before the pandemic. Part 3 of this chapter addresses three such proposals, concluding that no meaningful change will occur without a realignment of institutional resources outside a crisis response. The pandemic caused more people than ever before to die alone in ways that were unpredictable and traumatic. Mitigating this will require renewed focus on the relationships that give people’s lives meaning, and reconfiguring the institutional arrangements which support the agency these relationships facilitate.

---


Could the Pandemic be a Tipping Point for the Importance of ACP? Results from the Netherlands and from the American Midwest

This section will examine two cultures’ responses to the pandemic, and begin laying the groundwork for what I will argue is a better approach: namely, making ACP more accessible so that older and chronically ill people can plan for the care they need without risking exposure or traumatic institutionalization. One study found that people in the Netherlands tended to see the pandemic as reason to talk through care preferences with their doctors. Although they were initially more concerned with details such as the availability of ICU beds, their physicians were able to guide them through the kinds of care that could be provided at home with less exposure risk. Comparatively, according to another study, Americans were not as motivated by the pandemic to discuss their end of life care preferences. People who were sicker tended to be more ambivalent about the virus, and this ambivalence was also correlated with psychosocial determinants of health. The first step toward coping with decline and death is to acknowledge these realities, and disasters such as COVID-19 have revealed that we are still avoiding doing so.

Recently, a Dutch survey of general practitioners (GPs) found that the pandemic motivated engagement in care planning conversations, especially for those at high risk for dying of COVID. Janneke Dujardin et al’s 2021 article “The COVID-19 pandemic: A tipping point for advance care planning? Experiences of general practitioners” surveyed fifteen GPs, and identified six major themes in their care provision during COVID.¹¹ Key themes included the urgent need for ACP, the GP’s perceived role in conducting it, and essentials for good communication.¹² Physicians reported that news media was found to fuel patients’ anxiety about

¹¹ Ibid., 1238.
¹² Ibid.
the pandemic, and motivated their patients to bring up their care preferences.\textsuperscript{13} One physician noted that many patients seemed to focus on the availability of ICU beds instead of considering the kinds of care that could be provided at home with less exposure risk.\textsuperscript{14} Digital communication presented a barrier for some, while others found it a viable alternative given the circumstances.\textsuperscript{15} In both cases, the majority of physicians surveyed reported that familiarity with the patient and having a shared history was a key factor in facilitating good communication during ACP.\textsuperscript{16}

Aside from the growing recognition among GPs that ACP is a valuable process which can help avoid crisis management, the pandemic brought about two further changes: “…the recognition of the importance of specifically discussing ICU admission during [ACP]… [and] the importance of discussing loneliness and its relationship with hospital and nursing home visitation policies, quarantine and isolation.”\textsuperscript{17} If the COVID-19 pandemic represents one tipping point that should signal the importance of considering end of life care preferences before the onset of illness, ICU admission is perhaps another tipping point: once admitted to the hospital, caregivers are legally required to provide life-sustaining treatment unless the patient has a physician’s order indicating otherwise. For example, an 85 year old who is already suffering from chronic kidney disease will not only receive routine dialysis, but also full CPR and likely hospital admission should they contract COVID-19 and have trouble breathing. This may not be

\textsuperscript{13} Ibid., 1242.
\textsuperscript{14} Ibid.
\textsuperscript{15} Ibid., 1244.
\textsuperscript{16} Ibid.
\textsuperscript{17} Ibid.
the most humane way of caring for a chronically ill elderly person who probably would not want to spend their potential last days in isolation from their loved ones. Being institutionalized can be traumatic— even if the process is more gradual, being alienated from one’s relational network can intensify extant health problems such as dementia. Thus, the pandemic compounds the risk of suffering and dying alone, whether people are quarantining at home or in isolation in a health care facility.

Dujardin et al’s study also found that when physicians delegated care planning conversations to the practice nurse, patients “…found it difficult to talk with the nurse specialists…”. Patients “felt belittled due to the framing of the question.”18 The language in this part of the article is somewhat unclear, but it seems patients preferred to speak with the GPs rather than nurses about their care preferences, and that physicians thus made greater efforts to engage with them. So, despite feeling pressed for time and the need to delegate, ACP conducted by other practitioners did not prove efficacious due to patients wanting contact with their doctors.

It is questionable whether patients in the U.S. would feel similarly belittled if another role of health practitioner attempted to discuss care preferences at end of life. I surmise that because so many Americans do not have access to a GP with whom they have built trust, they might be more willing to engage with different types of practitioners—especially if they could achieve similar results at decreased cost. One of the Dutch physicians said to the researchers “[w]hat is unique of being a GP: patients have an intrinsic trust in you, which results in them being very honest. That’s beautiful.”19 I question whether the majority of Americans have comparable

18 Ibid.
19 Ibid.
intrinsic trust in their physicians, or even a relationship with a physician given that many Americans do not have affordable access to health care. In the U.S., clinicians did attempt to discuss “poor prognosis for older patients developing respiratory failure, but frontline clinicians informally report that many families had difficulty accepting recommendations for comfort care.” Without a relationship with the physician, this response is understandable: who would want to accept a poor prognosis from someone who hardly knows them? An approach which puts people into closer contact with a range of practitioners earlier on would help avoid these scenarios.

Meanwhile, evidence suggests patients in the U.S. are not well informed and somewhat indifferent about the risks of COVID-19. Many of those who are at high risk are not changing their routine in ways that acknowledge the possibility of dying from the virus. In “Awareness, Attitudes, and Actions Related to COVID-19 Among Adults With Chronic Conditions at the Onset of the U.S. Outbreak: A Cross-Sectional Survey”, Michael S. Wolf et al drew from the Chicago COVID-19 Comorbidities (C3) Survey and the Health Literacy and Cognitive Functioning Among Older Adults cohort study to identify older and middle-aged socio-demographically diverse people living in the Chicago area with one or more chronic conditions who might be at greater risk for COVID-19. 630 participants were given a telephone survey with a short set of questions regarding their attitudes about COVID-19. The results are not what might be expected:

---


22 Ibid., 6.
The threat of a COVID-19 outbreak was rated to be more serious by adults aged 70 years or older and by women before adjustment; those with 3 or more chronic conditions rated the threat as less serious than those with fewer conditions. Black participants were more likely than white participants to report that they were “not worried at all” about getting the coronavirus; this was also true for those reporting poorer health. Women\textsuperscript{23}, Black and Hispanic persons, those with LEP [low English proficiency], those living below the poverty level, those with lower health literacy, and unmarried persons were significantly more likely to respond that it was “not at all likely” that they would get COVID-19.\textsuperscript{24}

While the greater frequency of adults 70 or older rating COVID-19 as a threat is not necessarily a surprise, it is startling that people with 3 or more chronic conditions were less concerned about COVID than those with fewer. Perhaps this is because they are more at peace with the possibility of dying, although it could also signal a lack of awareness and overconfidence about their wellbeing. It is also concerning that Black participants and participants whose health was poorer were increasingly likely to report they were not worried about getting COVID, and that people who are already coping with low income, low health literacy, low English proficiency, and the lack of a domestic partner were more likely to discount the possibility of their contracting the virus and becoming sicker.

Although being worried about the virus does not necessarily correspond to taking action or making supposedly health-promoting behavioral changes, Wolf et al.’s evidence suggested that many chronically ill Chicagoans were unlikely to do either. Of the participants surveyed:

- Nearly one third could not identify symptoms or proper measures to prevent infection. Most respondents reported that the virus was affecting their daily routine and leading to changes in already-made plans, yet 1 in 5 adults believed that it had little to no effect on their lives or plans. Nearly 1 in 3 participants believed that they were only a little or not at all prepared for a COVID-19 outbreak, whereas just 1 in 5 believed that they were very prepared. Only 1 in 10 respondents was very confident that the federal government could prevent a nationwide outbreak of the virus.\textsuperscript{25}

\textsuperscript{23} Although being a woman did predispose participants to report they were “not at all likely” to get COVID, women were still more likely than men to rate the seriousness of the COVID-19 threat as high (Wolf et al., 6).

\textsuperscript{24} Ibid.

These are nevertheless significant figures: among those who were already chronically ill and coping with barriers to care, only two-thirds would be able to identify symptoms or be prepared to prevent infection. A fifth believed COVID will have no effect on their lives or plans, and a third felt they were only a little or not at all prepared for a COVID-19 outbreak. It could still be the case that the other four fifths of participants are concerned about the way COVID will affect them, and they could even be taking active measures to document their end of life care preferences. Nevertheless, this is unlikely given that so many people felt unprepared or indifferent. It is troubling that psychosocial determinants of health in the U.S. are correlated with ambivalence about the virus. Those who are most deserving of support from the health care system are least likely to see the pandemic as serious enough to engage with clinicians, and least likely to have documented preferences or a surrogate decision maker if their health worsens. Americans have been less likely to see the pandemic as a tipping point or as motivation to talk with their friends, relatives, relatives and health care providers about end of life care preferences. Instead, we tend to ignore or minimize the problem, responding to the crisis in ways that make it much more likely we will suffer and die intolerably. The next section will focus on the ways the pandemic has worsened injustices already faced by older and chronically ill Americans, making the possibility of an appropriate death more elusive.

**COVID-19 in the U.S.: An Exacerbation of Existing Injustice and the Increased Elusiveness of Appropriate Death**

This section examines the disproportionate impact of COVID-19 on older and chronically ill persons. Some of the impact was direct: more older people ended up isolated in institutions without family or friends to visit and care for them, while official responses tended to focus on technological solutions such as ventilator access rather than forms of social support which could have played a beneficial preventative role. Doctors reported having to make more best interest
decisions under pressure than ever before, with no time to consult with family members or other care providers about what their patients may have wanted. There were indirect effects on the wellbeing of older adults as well. They were much more likely to suffer neglect by care staff who were also contracting the virus, while the lack of group activities negatively impacted psychosocial health and worsened dementia symptoms. Quarantine mandates contributed to family clustering, with the result that patients facing health crises were more likely to be treated as unrepresented when their COVID-positive relatives could not be present to support them. Family members experienced new forms of guilt and denial on behalf of relatives who suffered and died from the virus.

This section closes by introducing the concept of an appropriate death, devised by psychiatrists Avery Weisman and Thomas Hackett to address how people might die in ways which they can accept, and which are acceptable to their loved ones and to the social groups to which they belong. The COVID-19 pandemic has made it clear that we ought to do better with respect to helping our elders die well; as Jennifer Parks and Maria Howard argue in the article “Dying well in nursing homes during COVID-19 and beyond: The need for a relational and familial ethic”.26 Our lack of preparedness has deprived hundreds of thousands, potentially millions of people of an appropriate death, instead subjecting them to unpredictable, traumatic death processes. I agree with Parks and Howard that the problem is indeed relational: we have not thought through or prepared for the kinds of activities that would allow for a tolerable decline or an appropriate death. I end this section by proposing that ACP should be among these

---

activities, and begin to sketch out my position that it would be valuable to include and retrain direct care workers to expand access to productive ACP discussions.

Older adults in the U.S. have been among the groups hurt most by the pandemic, as noted by Tia Powell, Eran Bellin and Amy R. Ehrlich in the article “Older Adults and COVID-19: The Most Vulnerable, the Hardest Hit”. Despite the fact that “Americans eighty-five and older make up only 2 percent of the U.S. population, they comprise 30% of those who have died from COVID-19.” The mortality rate increased with the age of patients, and the benefit of acute treatment interventions such as ventilators declined. Globally, and perhaps especially in the U.S., efforts focused on “finding, building, and buying ventilators” rather than supporting older and chronically ill people at home or in nursing homes. For those who did go to the hospital, “…decision-making for seriously ill patients was hampered by the exclusion of family members from the bedside.” More people than ever before ended up isolated in institutions, and facing death without anyone familiar to care for them or attend to their last wishes. Significantly, failed quality measures in nursing homes was not necessarily correlated with increased mortality: instead, the number of nursing home deaths is linked “…to the size of the facility and to being located in a dense urban environment, with high background rates of Covid-19 infection…”.

28 Ibid.
29 Ibid.
30 Ibid.
31 Ibid.
32 Ibid., 62.
Skilled nursing facilities often recognize that they are the expected end point for nursing home residents, and some did manage to provide good quality end-of-life care despite the pandemic.\(^{33}\)

Once again, isolation protocol meant that fewer caregivers and family members could be present to support dying patients at the bedside, while difficult end of life decisions had to be made at a much more rapid pace. This put greater pressure on the treating physician, who is ultimately responsible for offering or withholding life-sustaining treatments. In “Crisis Standards of Care: Lessons from New York City Hospitals’ COVID-19 Experience: A Meeting Report”, Toner et al. note that triage decisions needed to be made even more quickly, and cannot wait for “a cumbersome committee structure”.\(^{34}\) They argue that we ought to develop better rapid decision making processes that involve the treating physician, and also other physicians.\(^{35}\) These authors also call for education, which presumably would be education for doctors about how to support potentially dying patients and engage with families, although they are not specific regarding what kind of innovations would be of benefit.\(^{36}\)

Toner et al use the language of the “treating physician”, which one might infer is distinct from a patient’s general practitioner or perhaps palliative care physician. To articulate this point in another way: physicians in the emergency department faced unprecedented demand to stabilize patients in crisis without being able to get to know them, their families, or their other care providers. They have been forced more than ever before to make best-interest decisions for patients who are too sick to understand their condition or communicate their wishes. The

\(^{33}\) Ibid.


\(^{35}\) Ibid.

\(^{36}\) Ibid.
persistent problem of inadequate preparation for end of life care in the American health care system, along with the tendency to spring into crisis response has thus been magnified by the pandemic.

COVID-19 has also made it more difficult for staff at nursing homes to provide quality care for residents. Family members and friends who may have ordinarily visited and helped provide care and meaningful emotional support were prohibited from doing so. Though more than 90,000 long-term care residents had already died from the virus as of November 2020, advocates for the elderly report that tens of thousands more are dying from neglect by overwhelmed staffs and slow declines from isolation.\(^37\) Initial findings about the consequences of neglect are dismal:

Nursing home expert Stephen Kaye, a professor at the Institute on Health and Aging at the University of California, San Francisco, analyzed data from 15,000 facilities for the Associated Press, finding that for every two COVID-19 victims in long-term care, there is another who died prematurely of other causes. Those “excess deaths” beyond the normal rate of fatalities in nursing homes could total more than 40,000 since March. The more the virus spread through a home, Kaye found, the greater the level of deaths recorded for other reasons, suggesting care suffered as workers were consumed with attending to COVID-19 patients or were left short-handed as the pandemic infected employees themselves.\(^38\)

The tragic but predictable consequence of increased demands being placed on care workers is that older people will have fewer people to help them eat, change, wash up, and get to the toilet. Nursing care workers are getting sick themselves, and staffing challenges have intensified. Genuinely distressing stories are emerging regarding the neglect occurring in the wake of the pandemic. One retired 75 year old truck driver managed to avoid contracting COVID, but became so malnourished and dehydrated that he dropped to 98 pounds and appeared to his son as

---


\(^{38}\) Ibid.
though he had been in a concentration camp. He died of aspiration pneumonia, suggesting that he had choked on his food, while septic shock suggested an untreated urinary tract infection and E. coli in his body from feces suggested poor hygiene. Others died of dehydration, starvation, or infected bedsores. As Powell et al. note, Americans tend to fixate on technological solutions in health care rather than changing health care infrastructure so that nursing homes and their staff along with homebound older adults and home care workers can get the support they need. The result is that older and chronically ill people die alone, painfully, and in ways that could have been prevented.

Meanwhile, people living in retirement communities and nursing homes are experiencing increased fear, grief and loneliness because social distancing measures have disrupted routines and activities. Enjoyable events such as shared meals and games are restricted, and residents are forced to cope with living in close quarters with other infected people, as well as the possibility of dying alone. Cary Johnston, a North Carolina retirement community resident could not visit her husband in the skilled care unit for more than three months because of isolation restrictions. “He is in a golden prison, and so am I,” she says. “I know he is not going to live forever, and neither am I. But I don’t want to lose him this way.” Gary Barfield, a 76 year old Air Force

---

39 Ibid., 2.

40 Ibid., 2.


43 Ibid.

44 Ibid.

45 Ibid.
veteran in Missouri, compared living through the virus to fighting in the Vietnam War: “losing that many people in such a short time was hard to take.” One retiree felt her work in a laboratory helped prepare her for life in quarantine: “Look, if it’s a choice between being bored and being dead, I know which one I’d go for.” Despite facing neglect and alienation, many older adults are showing remarkable resilience; coping actively with a global catastrophe.

The increased likelihood of neglect in nursing homes is one underacknowledged but serious consequence of the pandemic, and the measurable impact of social distancing and isolation protocol on older adults’ mental health and dementia status is another. Riccardo Manca et al. conducted a meta-analysis of articles regarding how social isolation has affected older adults with and without dementia during the pandemic, summarizing their findings in the article “The Impact of COVID-19 Infection and Prolonged Social Isolation on Neuropsychiatric Symptoms in Older Adults With and Without Dementia: A Review”. Many initial studies focus on the pandemic’s direct impact on people’s physical and mental health, but equally important are the psycho-social consequences of coping with a lack of social support and loneliness. Thus, Manca et al. consider both the direct impact of the virus on neuro-psychiatric symptoms, as well as how changes in psycho-social experience impact these symptoms.

Perhaps unsurprisingly, contracting COVID-19 made older adults without dementia more likely to experience neuropsychiatric symptoms, pushing them closer to a dementia diagnosis;

46 Ibid.

47 Ibid.


49 Ibid.
while older adults with dementia were more likely to experience agitation and delirium while fighting the virus. A multi-institution study of 125 patients without dementia who were ages 60 and above found that 31.2% presented with altered mental status (i.e. acute alteration in personality, behavior, cognition or consciousness) in addition to COVID upon admission to the hospital.\textsuperscript{50} According to the judgment of the clinicians who admitted them: “As many as 59% of these patients met criteria for psychiatric diagnoses, with the great majority being new cases of psychoses, neurocognitive disorders, and affective disorders.”\textsuperscript{51} In another study, for COVID patients who already had dementia, all presented with agitation in the ED, and more than 85% were suffering from delirium.\textsuperscript{52}

Manca et al. report that results were mixed regarding the impact of social isolation on older adults without dementia; although, for those already coping with dementia, social isolation was much more strongly correlated to worse symptoms, and even caregiver distress. One online study of 833 healthy older adults who were forced to isolate found no significant difference in self-rated mental health for adults ages 60-70 and 70 and above.\textsuperscript{53} Another study of otherwise healthy older adults found that those with a younger “subjective age” or perception of themselves as younger than their actual age made them more resilient during quarantine.\textsuperscript{54} However, those with an older subjective age reported increased levels of stress, anxiety, and depression when


\textsuperscript{52} Ibid., 4-5.

\textsuperscript{53} Emerson, Kerstin Gerst. “Coping with Being Cooped up: Social Distancing During COVID-19 Among 60+ in the United States”, 4.

these were associated with loneliness. With respect to older adults with dementia forced to quarantine, one compelling study found direct correlations between both the length of a person’s social isolation and the severity of their dementia symptoms, as well as the length of their isolation and the distress experienced by their caregivers. Otherwise, the majority of studies examined by Manca et al. suggest a link between social isolation and dementia symptoms, and that the pandemic has intensified risks for older adults with or without a dementia diagnosis.

Another underacknowledged threat is the phenomenon of family clustering, or when multiple members of a household or extended family unit contract COVID-19 at the same time in the same location. This is distinct from infection clusters in nursing homes or workplace facilities, where workers interact with residents and vice versa. These facilities often have protective protocol, and interaction is not as intimate or spontaneous. In the article “In This Together: Navigating Ethical Challenges Posed by Family Clustering during the COVID-19 Pandemic”, Nicole Van Buren et al. discuss the three novel issues in health care that emerge as a result of family clustering. Many authors including Van Buren point out that when multiple members of a household contract the virus at the same time, this limits the potential surrogates who can be available at the bedside. But now, thanks to the virus, more patients are being

---

55 Ibid., 1204.
60 Ibid.
61 Ibid., 17.
treated as unrepresented because their relatives are sick or quarantining. Unrepresented patients are those who “lack decision-making capacity but have no advance directive and no one to serve as a legally authorized surrogate.”

Second, family clustering can lead to a unique combination of guilt and denial among those family members who serve as caretakers or decision-makers. Van Buren et al. observed family members were more likely to experience guilt, shame, and denial around the possibility that they may be responsible for their relative’s infection or death. What is new with respect to guilt and shame is that a family member could rightly attribute themselves to be the cause of a relative’s death: this was far less common before COVID. Family members’ experience of denial is also potentially exacerbated, since it is no longer unusual for “…a surrogate to have recent, firsthand experience of the very same infection, to have survived it, and for this to be not merely the evidentiary basis but also the embodied basis of their denial or disagreement with their loved one’s prognosis.” It was not uncommon for patients’ relatives to take issue with a negative prognosis before COVID, but now there may be a form of denial specific to COVID that further complicates the family’s ability to trust the health care team. Finally, social inequities such as lack of affordable housing, likelihood of being an “essential” worker, and lack of access to insurance and quality health care make the burden of COVID-19 worse for Black, Indigenous

62 Ibid.


65 Ibid.

66 Ibid.

67 Ibid.
and Latinx people.\textsuperscript{68} The fact that these groups are more likely to live in multigenerational households and thus experience family clustering also means that they stand to suffer more due to the pandemic.\textsuperscript{59}

This is not to say that older and chronically ill people necessarily fare better in an institutional setting: as I noted previously, the psycho-social consequences of isolation and the increased likelihood of neglect are serious problems for quality of life during the pandemic. But there is also evidence that different types of institutions have discharged patients in response pressure to maintain a low death rate. Some nursing homes sent sick residents to the hospital: a rehabilitation and nursing facility in New York sent 18 residents with DNR orders to various local hospitals in May 2020.\textsuperscript{70} Likewise, hospitals in the UK were accused of sending patients back to care homes without any evidence of a negative test or even back after a positive test, although standards for testing at the time were somewhat ambiguous.\textsuperscript{71} Either way, because coping with death can inspire pain and resentment among caring networks, it is unsurprising institutions have done what they could to avoid responsibility and damage to their reputations.

COVID-19 has also deprived people of the opportunity to have what psychiatrists such as Avery Weisman and Thomas Hackett conceived of as an appropriate death.\textsuperscript{72} Weisman attributes four key features to an appropriate death: a person must have “awareness” that they are dying,

\textsuperscript{68} Ibid.

\textsuperscript{69} Ibid., 19.


\textsuperscript{71} Oliver, David. “David Oliver: Let’s Be Open and Honest About Covid-19 Deaths in Care Homes,” m2334.

they should have achieved “acceptance” of impending death, their death is “timely” in the sense that they are not dying too early or late with respect to their lifespan and treatment process, and finally that they have a “propitious” death, or one that is in accordance with the values they have endorsed, perhaps as a result of membership in a chosen group.73 Because of the pandemic, people are much more likely to receive news of a terminal prognosis alone, without friends or relatives to provide emotional support, and with a care team that stands to increase the spread of the virus the more time they spend at the bedside. These circumstances make it much harder to accept the possibility of dying, and are already responsible for many untimely deaths. For those groups who may not have appropriate access to clinicians and who lack advance directives or surrogate decision makers, a propitious death is that much more elusive. Advance care planning is among the tools that can help people plan for end-of-life, a possibility that COVID-19 has exacerbated in ways that go beyond pre-pandemic barriers to care.

In the article “Dying well in nursing homes during COVID-19 and beyond: The need for a relational and familial ethic” Jennifer Parks and Maria Howard advocate for renewed consideration of the kinds of relationships that give people’s lives meaning, whether they are living or dying.74 They build from Weisman and Hackett’s concept to argue that dying appropriately involves more than just avoiding unwanted hospitalizations or treatment procedures, it can also involve making amends, participating in meaningful activities, or visiting with friends and relatives.75 Advance care planning can be a part of this process, but the context

75 Ibid.
of the pandemic requires that we change our approach to it in several key ways. Namely, we should find ways to help loved ones be present at the bedside (even if only virtually), train providers and caregivers to engage in conversations they have historically sought to avoid, encourage even healthy elders to consider and express their wishes and preferences about end of life, and address shortages of staff and technology that impede agency and quality of life for older and chronically ill persons.

I appreciate these authors’ inclusion of ACP as one among many viable approaches to dying appropriately. Chronically ill and older adults were coping with loneliness well before the pandemic, and now official mandates for social distancing and isolation have made it even more difficult for people to interact in ways which allow them to support one another. This has had deadly consequences: people in institutions have been forced to cope with intensified alienation and neglect, while people in multigenerational homes risked contracting the virus and ending up hospitalized. Once hospitalized, it is far more difficult to think through and express care preferences, especially when friends and relatives or trusted care providers cannot be present for support. This has needlessly subjected many older and chronically ill people to traumatic suffering and death.

While I concur that barriers to an appropriate death are relational in nature, I argue throughout this project that certain kinds of relationships are needed to facilitate the agency which allows people to navigate the health care system even when they are relatively healthy. It is even more important for these relationships to form in ways which challenge the disenfranchisement experienced by older, chronically ill people and the people who provide their

---

76 Ibid.

77 Ibid., 595.
everyday care and assistance. These are issues I will address in Chapter two of this project, which incorporates a theory of agency as well as a theoretical method for restoring it through what philosopher Hilde Lindemann describes as counterstories. The COVID-19 pandemic has demonstrated that these collaborative relationships have atrophied significantly—supposing there was functional collaboration in the first place. As I will argue in Chapter three, the health care system has a responsibility to ensure that people are able to navigate it in ways which respond to their needs. This project will advocate for the value of ACP in Chapter five, and propose an alternative approach to it in Chapter seven. Therein, I will argue that direct care workers’ practice gives them enhanced insight into the kinds of considerations that make chronically ill and dying people’s lives meaningful. This moral and practical acumen situates them as especially qualified to help patients plan for end of life care should they pursue an additional certification in ACP. These measures would have had a positive impact on end of life care before the pandemic, and now they are all the more necessary as a result of it.

Aspirational Approaches to ACP in the U.S. in Response to the COVID-19 Pandemic

Throughout the U.S., calls for greater focus on ACP have been largely aspirational, and have tended not to address the relational barriers to its successful practice that existed even before the pandemic. Thus, this section will consider the practicality of some proposed changes to the infrastructure and provision of advance care planning, along with some technological developments that could improve the delivery of care at end of life. Noting the strain the pandemic has placed on the health care system, Dr. J. Randall Curtis recommends greater priority be given to ACP; more specifically, Curtis proposes the possibility of “informed assent” (rather than informed consent) whereby the patient or family member gives the physician
responsibility for end of life decision making when appropriate and desired. Dr. Brian L. Block also expounds upon the value of ACP, and proposes that all kinds of clinicians (MDs, RNs, pharmacists) as well as all allied health professionals (dieticians, physical and occupational therapists, etc.) should engage in ACP with outpatients using a simple, three-step question process. Finally, Dr. Vipul Bhatia discusses how WellSpan Health, a system of 8 hospitals and over 170 outpatient facilities in central Pennsylvania and northern Maryland, responded to the failures in their pre-pandemic approach to ACP by creating and training an Advance Care Horizon Planning Response Team to conduct virtual discussions with high risk patients.

In what remains of this section of the chapter, I will address the potential strengths and shortcomings of each of these approaches. I conclude that each one fails to grasp the relational configurations which ought to provide people with adequate support to consider and communicate their end of life care preferences.

In “The Importance of Addressing Advance Care Planning and Decisions About Do-Not-Resuscitate Orders During Novel Coronavirus 2019 (COVID-19)”, Dr. Curtis et al. propose that now is the time to promote and conduct care planning discussions so that patients can have care which is concordant with their goals. Discussions about end-of-life care should be high-priority among clinicians for three reasons: clinicians should always avoid prescribing life-sustaining treatments when unwanted by patients, these treatments should be avoided particularly when


79 Ibid.


health care capacity is under stress, and finally that “…provision of nonbeneficial or unwanted high-intensity care may put other patients, family members, and health care workers at higher risk of transmission of [COVID-19].” These are significant pressures for the health care system, and Curtis et al. correctly cite them as greater reason to make advance care planning a standard for care.

These authors also draw attention to the problem that discussions of code status and the use of CPR can tend to shut down more meaningful exploration of patients’ values and goals for treatment. Nevertheless, because inappropriate or unwanted CPR presents a serious and avoidable risk for health care workers, establishing code status must remain a priority.

Although most DNR (do-not-resuscitate) orders can be established through standard informed consent, Curtis et al. point out that the pandemic has expanded the likelihood that patients with multiple underlying health conditions will have emergencies that would warrant CPR. Even though unilateral DNR rarely had a role before COVID-19, the risk imposed by the pandemic could make it appropriate in some extreme situations at present. Preferable to unilateral DNR, however, would be a process Curtis et al. refer to as “informed assent”, which begins with an assessment of the patient’s values and goals, and can then shift decision-making responsibility to the physician if the patient and surrogate feel it is appropriate.

---

82 Ibid.
83 Ibid.
84 Ibid.
85 Ibid.
86 A process whereby the physician orders the withholding of life-sustaining treatments without the input or formal consent of surrogate decision makers (Curtis et al, 1771).
87 Ibid., 1772.
88 Ibid.
Informed assent has the advantage of streamlining decision-making; avoiding the cumbersome committee structure that Toner et al. do not believe has a place in crisis standards of care. But it is unclear which physician is meant to initiate discussions about patients’ goals and values, or when they should begin the process. If a specific role of physician is not deemed responsible, it will likely fall to emergency physicians who will have to address deeply held emotions in crisis scenarios, with patients they may not know well. Well before the pandemic doctors cited lack of time and issues with continuity of care as reasons they avoid end of life care discussions. Certainly these issues have been made worse by the pandemic. It is also unlikely that doctors will prioritize re-educating themselves on how to provide sensitive, compassionate end-of-life care when they are under more pressure than they have been in decades to save lives at all costs. It is insufficient to reinvoke unilateral DNR as a result of medical futility and then propose informed assent as a more palatable alternative. Instead, we ought to attribute responsibility for care planning discussions to a specific role of health care practitioner, and give them the resources to engage with patients over time. This could be done while patients are still healthy, and perhaps even in an outpatient capacity. Because the underlying relationships are already strained, some reconfiguring of them is necessary for more people to have their goals for care established, and for health care workers to avoid unnecessary risk.

Instead of attributing additional responsibility to physicians, we could more carefully consider who is already tasked with caring for older, chronically ill adults, and give them the training and resources to conduct ACP in an auxiliary role. In general, direct care workers

provide essential support services to disabled and older adults.\textsuperscript{90} They take on a range of responsibilities, varying from helping with activities of daily living such as eating meals to more complex tasks such as managing medications and finances. In all of what they do, they must sensitively consider their charge’s needs and desires, and they succeed when they help that person live well through their day. Despite what many would take to be a valuable skill set, these workers are significantly underrecognized. I will argue throughout this project that their expertise as caregivers also situates many of them to anticipate the concerns that make for an appropriate death.

A more expansive approach proposed by Block et al. is that clinicians (i.e. nurses, doctors, pharmacists, etc.) and allied health professionals (dieticians, physical and occupational therapists, etc.) could all take responsibility for care planning discussions.\textsuperscript{91} The need to establish meaningful boundaries about potentially unwanted lifesaving treatments is dire, and this approach would provide patients with more opportunities to explore and document their goals. Block et al. suggest that care discussions could unfold in a three-step process: clinicians could ask the patient to select a surrogate decision-maker, encourage them to talk with this person and document their wishes in an AD, and then follow up on documentation.\textsuperscript{92} Health systems should also invest in novel communication methods such as online AD portals and even automated calls to disseminate ACP materials and “prime patients for ongoing ACP discussions”.\textsuperscript{93}


\textsuperscript{91}Block, Brian L., et al. “During COVID-19, Outpatient Advance Care Planning Is Imperative: We Need All Hands on Deck,” 1396.

\textsuperscript{92}Ibid.

\textsuperscript{93}Ibid.
Block et al.’s approach may expand potential opportunities to engage in ACP discussions, but the underlying relational framework that would lead to a good quality discussion is still underdetermined. Involving more roles of health care practitioners is not necessarily valuable unless they receive education regarding how to engage in end of life care discussions. Being prompted to establish a surrogate decision maker by a physical therapist or dietician would probably be uncomfortable without a history of trust and support; after all, results from the Netherlands suggested that patients were resistant to having ACP discussions with advance practice nurses.\footnote{DuJardin, Janneke, et al., “The COVID-19 pandemic: A tipping point for advance care planning? Experiences of general practitioners,” 1244.} It is perhaps more expected of physicians and nurses to ask about surrogate decision makers, but they must also educate themselves and invest time in building trust with patients about supportive relationships in their lives. Practitioners involved in ACP should have site-specific education about advance directive laws in their state, or the discussions they facilitate may fail to bring relational networks or documents into the scope of institutional awareness.

Furthermore, receiving an automated call, text, or email from one’s local health system is likely to alienate older and chronically ill people, and potentially give them the impression that the institution is not invested in a genuine conversation about their deeply-held preferences. Imagining how an unsuspecting older person might react to such a call is darkly comical—as the gesture could convey that the institution is more concerned with one’s death than one’s life and relationships. Technology is not necessarily helpful unless the relational starting point was empathic communication which developed into trusting relationships over time.

It is possible for health care institutions to respond to the need for empathic communication about decline and death, although I take Block et al to have oversimplified the
process in ways which do not necessarily build trust with patients. It would be better to offer ACP training to direct care workers specifically, for they are already expected to navigate sensitive communications with their patients or clients as a part of their daily work life. Employing them in an auxiliary capacity in a hospital-associated ACP department would give them some official standing to lead conversations about care preferences, and potentially allow more people to more proactively seek them out. Outreach efforts could thus proceed with greater respect for the kinds of interactions that build trust and make way for what is perhaps the most difficult conversation a person will ever have.

Among more successful examples was Wellspan Health, a multi-institution health system in south central Pennsylvania and Massachusetts. They were able to provide greater access to end of life care conversations during the pandemic, although a redistribution of institutional resources was still necessary to ensure these results. Regardless of their relationship to direct patient care, all staff were trained in the importance of ACP and given a sense of their role in supporting it through online curricula, in-person training and follow-up support. Integrating the Respecting Choices model and Five Wishes advance directive form, ACP teams were led by an executive administrator, a physician-lead, a full-time ACP coordinator, and full-time program manager. They were responsible for supporting the practitioners who went on to engage in care planning conversations, and ensure good quality results. Known as the “Horizon Planning Response Team”, the group of care planners included “MAs, social workers, LPNs, RNs, and certified registered nurse practitioners…” who received additional training on care planning


96 I will describe this approach in more detail in Chapter 5, “Why Practice ACP: A Case for Holding”.

97 Ibid., 4.
methods and outreach, along with education about how to use virtual communication.\textsuperscript{98} This system resulted in more people having access to a provider who could build a relationship with them, address their preferences over time, and ensure that these were documented in ways that would be recognized by the institution.\textsuperscript{99}

However, the 35 members of the Horizon Planning Response Team who engaged in outreach and care planning discussions were available because they were furloughed due to practice shutdowns.\textsuperscript{100} In other words, getting the necessary personnel for successful ACP was only possible because of a crisis mode brought on by the pandemic. Yet again, we sprang into action because of a crisis rather than confronting the need for a more thoughtful approach to end of life care. Whether the institution would continue to justify the need for such a team under ordinary circumstances is unclear, although the results demonstrate the value of this approach. Instead of deputizing furloughed practitioners, we could recognize that direct care workers already navigate sensitive conversations about care preferences in ways which would provide better support for older and chronically ill people. The disastrous results of the pandemic show us that facilitating appropriate deaths should be among the priorities of the health care system, and that we ought to better mobilize practitioners to carry out this goal.

\textbf{Conclusion}

It might be hoped that the pandemic would give Americans reason to consider their values about end of life care or what they would want for their loved ones. While it is not a panacea, good quality advance care planning can help facilitate an appropriate death: a timely

\begin{flushright}
\textsuperscript{98} Ibid., 5.
\textsuperscript{99} Ibid., 8.
\textsuperscript{100} Ibid., 5.
\end{flushright}
and recognized end that is in accordance with one’s values and goals. Yet, many people in
otherwise tolerable health are ambivalent about the risks of COVID and unmotivated to seek out
clinicians who could help them record their preferences or make resuscitation orders. They risk
being treated as unrepresented patients if an emergency renders them unable to communicate
with the care team, which is increasingly likely as the pandemic exerts a strain on everyone’s
physical health and psycho-social wellbeing. Meanwhile, people living in institutions cope with
these pressures along with the possibility of neglect resulting from staffing shortages. Older and
chronically ill people at home can suffer the consequences of family clustering, increasing the
likelihood that no one will be available to support them if they receive a terminal diagnosis once
hospitalized.

In comparison to the promising results from the Netherlands, the U.S. tends to lack the
infrastructure needed to give patients adequate access to GPs who can adequately engage in end
of life related conversations. Doctors had cited inadequate training and insufficient time to
conduct ACP prior to the pandemic, and the pandemic has put additional strain on essentially
every role of health care provider. It is far more likely that Americans will have their first clinical
encounter with an ED physician they have never met, who probably does not know their primary
care physician if they are fortunate enough to have one. Institutional safety requirements also
make it less likely they will have friends or relatives with them to help them communicate with
the care team.

Finally, current proposals on how to improve ACP do not necessarily address the
relational barriers to care that existed before the pandemic, and are insufficiently specific
regarding how to reallocate institutional resources. After all, the Horizon Planning Response
Team at Wellspan Health was the only approach with documented improvements to pre-
pandemic end of life care, but it relied on the labor of practitioners who had been furloughed from their ordinary work and retrained in ACP. These are all circumstances that can be changed, but it will take realistic reconsideration of the relationships involved in health care provision to have a meaningful impact.
CHAPTER TWO

CONTEXT FOR AUTONOMY

COMMUNITARIANISM, INDIVIDUALISM, AND AGENCY

Introduction

The previous chapter considered the impact of COVID-19 on older and chronically ill people, arguing that the tendency to avoid discussing end of life care preferences subjected many people to traumatic but avoidable deaths. In the conclusion of section two, I claimed that certain kinds of relationships are needed to facilitate the agency which allows people to navigate the health care system even when they are relatively healthy. This chapter will clarify the nature and function of agency, which I take to be conceptually prior to and separate from autonomous action and decision making. While the relational critique of autonomy has done a great deal to acknowledge the concrete barriers most people face in making choices,\(^1\) I contend that there is a meaningful difference between agency and autonomy which should impact how we conceive of persons and their choices. The fact that health care practices are ongoing and involve relationships is better characterized as agency rather than autonomy; agency is thus the context

\(^1\) For example, Diana Tietjens-Meyers’ theory of autonomy competency proposes that autonomous persons must have a set of coordinated skills that makes self-discovery, self-definition, and self-direction possible (Tietjens-Meyers, Diana. “Autonomy Competency” Self, Society, and Personal Choice. New York, Columbia University Press (1991): 77). Through relational engagement with the social world, individuals refine their understanding of themselves and are better able to steer their conduct and life plan in accordance with their ideals and desires (Ibid., 96). Carolyn MacLeod and Susan Sherwin also propose a relational approach to autonomy, arguing that autonomy ought not be seen as an individual achievement given how social and political structures condition forms of oppression which damage the capacities and opportunities of certain groups (MacLeod, Carolyn and Susan Sherwin “Relational Autonomy, Self-Trust, and Health Care for Patients Who Are Oppressed” Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self. Eds. Catriona Mackenzie an Natalie Stoljar. Oxford University Press (2000): 259-279, 260).
for autonomy. Among the aims of this chapter is introducing a socio-politically informed concept of agency, and explaining how agency can be restored through what bioethicist Hilde Lindemann describes as counterstories.

However, I will first examine some of the historical context that led to the rise of what some authors call “the autonomy paradigm”, and consider arguments for a communitarian approach to health care for aging and chronically ill persons. In the wake of interest in informed consent in the 1970s, emphasis turned to safeguarding patient’s rights and freedom of choice. By the late 80s, bioethicists Bruce Jennings, Daniel Callahan and Arthur Caplan became concerned that this emphasis on individual autonomous choice disadvantaged chronically ill and aging persons, who would derive greater benefit from community support and closer cooperation between healthcare providers. Callahan in particular advocates for a community-based approach to healthcare, and claims that liberalism and its central value of autonomy are too thin to guide ethical practice.

My concern in this section is that Callahan and the communitarian thinkers optimistically assume that cooperation toward mutual benefit is necessarily what undergirds health care provision. The ideal relationship of care is a cooperative one, but left unchecked, the health care system will remain a microcosm of overall socio-political injustice. Ideally, cooperation should be medicine’s foundation. But historically, and especially in cases of chronic illness, institutions have diagnosed and managed suffering in ways which have failed to address the challenges of diverse groups of patients. Given the history of medicine’s mistreatment of some oppressed groups, I argue in section two that libertarians such as Tristram Engelhardt are right to question

---

2 Jennings, Bruce, Daniel Callahan and Arthur Caplan. “Ethical Challenges of Chronic Illness,” 1.

the origin of institutional authority and to take a critical perspective on how health care resources are distributed.

However, one need not adopt a libertarian point of view to critically consider these problems. Libertarianism’s theoretical tendency to view persons as discrete entities who are not shaped by others or responsible for them cuts off meaningful possibilities for collective contestation of injustices in both the health care system and society in general. Although I find Engelhardt’s account of how authority can be manufactured persuasive, his notions of identity formation and community dynamics are underdeveloped. In response, I contend that although context and agency are prior to the identification and application of principles, we have the capacity to reflect on these and reengage them in a way that Engelhardt dismisses as redundant.

In section three, I explain and adopt Kathryn Abrams’ distinction between agency and autonomy. Drawing from the relational critique of liberal autonomy, Abrams describes how collective political contestation practices restore the agency of participants. This is similar to Hilde Lindemann’s theory of narrative repair as a means of restoring agency, and I take Lindemann to provide a valuable internal, psychological counterpart to Abrams’ socio-political analysis. Especially for older and chronically ill people who are forced to contend with infantilization and having their capacities ignored, a theory of agency which acknowledges the often invisible fight for everyday forms of self-directed action is significant.

While I affirm the moral value of Lindemann’s account of counterstories, I am concerned that she relegates sociopolitical considerations about the effects of counterstories to an empirical rather than moral-practical domain. I conclude that paying attention to the moral-practical effects of counterstories along with consideration of what Rebekah Johnston describes as external

---

factors would enhance the agency of patients and who stand to be disempowered navigating the health care system.

**A Communitarian Approach to Autonomy**

The 1986 publication of Tom Beauchamp and Ruth Faden’s *A History and Theory of Informed Consent* marked the culmination of decades of attempts to balance individual liberty and medicine’s duty to treat. Medical paternalism is the idea that a physician should do what they judge to be in the patient’s medical interest regardless of how patients perceive their own interest. This view dominated medicine as practiced throughout the early 20th century. The concept of informed consent emerged as a way of counterbalancing this approach. It’s central argument is that each patient has a right to be informed about their diagnosis and treatment options before consenting to undergo them. Interest in informed consent emerged in particular as a response to the atrocities committed by Nazi physicians who engaged in deliberately harmful research experiments on prisoners during World War II.\(^5\) The 1948 Nuremberg Code thus criminalized any experimentation on a human subject who does not consent to participate.\(^6\)

Afterward, emphasis in medicine and medical research shifted to what each person might consent to rather than what medical doctors should or should not do on their behalf.

Although there was renewed social focus on issues of informed consent in the mid-twentieth century, *A History and Theory of Informed Consent* considers Ancient and Medieval medical practices through their evolution in the twentieth century. This is significant in the sense that while the Enlightenment conceptualization of the rational individual had yet to emerge, Beauchamp and Faden found reason to scrutinize medical practices on the basis of how fair they

---


6 Ibid.
were to individual recipients. Many of the court cases which set parameters for informed consent practices in medicine involved plaintiffs who were middle-aged survivors of acute care or surgical interventions gone wrong, however, and this has perhaps contributed to the tendency to take competent adults as most capable of autonomy. From midcentury onward, the subject of autonomy merged with an ideal of decisional, competent adult persons who did not have to rely on others to consent.

Though informed consent was meant to empower patients and insist that the medical establishment respect patient rights, bioethicists became concerned that this approach to autonomy fails to consider the range of functions and relations each person must have in place to be able to make informed choices in one’s own interest. Quill Kukla offers an explanation of how the emphasis on informed consent has impacted respect for autonomy in practice. They note that while “…bioethicists know that the concept of informed consent does not exhaust the rich concept of autonomy, many still take it as a governing assumption that in the practical domain of health care, concerns about autonomy can be translated into concerns about self-determination, which can in turn be translated into concerns about informed consent.” Translating theory into practice in this way involves curtailing deeper considerations of a person’s autonomy in favor of more answerable questions about whether they understand key facets of their condition and can make independent, informed choices.

In the medical arena, the principle of autonomy was intended to structure and infuse informed consent practices, as Beauchamp claims in the 1979 Belmont Report—although Beauchamp also admits that the correspondence between autonomy and informed consent was

---

not theorized explicitly and seemed self-evident at the time.\(^8\) Kukla’s characterization of how an emphasis on autonomy translates to questions about self-determination and procedures of informed consent in practice is a central issue for critiques of autonomy. It is important that the connection Beauchamp assumed between autonomy and informed consent does not eclipse the ground of interpersonal relationships which make it possible for people to be self-determining.

Although the idea that the principle of autonomy motivates and justifies informed consent practices can seem unobjectionable prima facie, there are at least two key criticisms of this construct which are relevant to the agency of older, chronically ill patients and their caregivers alike. First, what communitarian authors call “the autonomy paradigm” may fail to capture the range of social supports required for both quality of life and good decision-making. This claim is the focus of the remainder of this section of Chapter two. Second, there is the problem that the principle of autonomy might be serving as both the motivation for an emphasis on informed decision-making and choice, as well as the retroactive justification for it. This is a criticism forwarded by libertarian theorist Tristram Engelhardt, and is the focus of the second section of Chapter two.

In the wake of the informed consent movement, Bruce Jennings, Daniel Callahan and Arthur Caplan responded with a critical consideration of how an emphasis on individual autonomy disadvantaged some groups of patients: namely aging and chronically ill persons. In 1984, two years prior to the publication of *A History and Theory of Informed Consent*, The Hastings Center began a three-year project on Ethics and Chronic Illness. The article “Ethical Challenges of Chronic Illness” is the result of this study, and was premised on the hypothesis that the individualistic perspective behind much of the moral discourse in bioethics would not be

\(^8\) Ibid.
of much benefit in the context of chronic and end of life care.\textsuperscript{9} Self-directed, autonomous decision making might seem important for otherwise healthy persons, but for people who are coping with chronic pain or dementia, the “good” choices often draw from a more limited range of options which get a person through the day or maximize moments of lucidity and orientation. People living in nursing homes’ range of choices is even more indexed to the resources of the facility and what their caregivers can help them do.

These authors critique the “autonomy paradigm” on the grounds that it is an inadequate approach to chronic and end of life care. There are three interrelated notions that form the basis of the autonomy paradigm: a medical model of illness, a contractual model of the physician-patient relationship, and an individualistic conception of personhood.\textsuperscript{10} In the medical model of illness, the disease is a threat and the goal of medicine is to restore the self to a state of health experienced prior to the onset of the disease.\textsuperscript{11} A contractual model of the physician-patient relationship takes the patient to be “a rational, self-interested subject, who, threatened by illness, voluntarily enters into a contractual agreement with a physician or other health care provider and temporarily submits himself or herself to medical authority in order to combat the illness.”\textsuperscript{12} Finally, an individualistic conception of personhood treats self-identity, autonomy and interests as conceptually prior to and apart from the experiences of illness and receiving care.\textsuperscript{13}

None of these conceptions apply to the experience of chronic care according to Jennings, Callahan and Caplan. They argue instead that reconceptualizing care in accordance with the kind

\textsuperscript{9} Jennings, Bruce, Daniel Callahan and Arthur Caplan. “Ethical Challenges of Chronic Illness,” 1.
\textsuperscript{10} Ibid., 8.
\textsuperscript{11} Ibid.
\textsuperscript{12} Ibid.
\textsuperscript{13} Ibid.
of care we ought to provide to those in decline would reorient us to the systemic and community-based nature of the goals of medicine. In chronic care, illness must be understood as a normal and enduring feature of a person’s experience: persons are in a state of constantly adjusting and managing disease symptoms with the help of various health care practitioners, relatives and forms of social support. The authors suggest that diplomacy is a better metaphor than warfare in this regard.\textsuperscript{14} Similarly, there are diverse roles patients will take on with various kinds of caregivers and health care practitioners. Chronic illness “tends to foster a wide variety of styles and stages of being a patient.”\textsuperscript{15} Furthermore, the view that the patient has a stable set of interests apart from their experience with illness is illusory. Good chronic health care provision involves “…assist[ing] the person in keeping the transformative power of illness under control, to integrate new subjective interests (wants) and new objective interests (needs) into a coherent and satisfying life.”\textsuperscript{16} The person in question lives within their particular body and social milieu, thus autonomy is not an abstract property of persons. It is “…an achievement of selves who are socially embedded and physically embodied…something that grows out of the physician-patient relationship, not something that presides over it.”\textsuperscript{17} This article concludes that emphasizing chronic care will create forms of mutual support and interdependency, and restore cooperation among communities of patients and providers.\textsuperscript{18}

While I believe Jennings, Callahan, and Caplan are right to call for renewed focus on the embodied, interpersonal struggles of chronically ill people and their caregivers, it is dubious that

\textsuperscript{14} Ibid., 10.
\textsuperscript{15} Ibid.
\textsuperscript{16} Ibid., 11.
\textsuperscript{17} Ibid., 12.
\textsuperscript{18} Ibid.
such a focus will reveal an extant functional network of social and institutional support. The scattershot organizational nature of the majority of direct care work complicates these communitarian authors’ assertion that we might simply uncover functioning relationships of interdependency if we took a closer look at chronic care. Home health is the largest employment sector for direct care workers, employing roughly 2.3 million of the total 4.6 million workers as of 2021.¹⁹ Unlike other occupations carried out in the public sphere, care work in private homes involves continual acts of maintenance performed without much support or oversight. As Jennifer Parks points out in No Place Like Home?: Feminist Ethics and Home Health Care, direct care work is not associated with a body of professional knowledge that requires mastery: instead, it is viewed as a form of common knowledge and thus rendered invisible as an important service to the community.²⁰ This makes it easier to take good care work for granted, while broad reaching standards which cut across various agencies are elusive. Furthermore, as has become clear over the course of the COVID-19 pandemic, the lack of organizational coordination in direct care work has been dangerous for workers and deadly for patients.

Elsewhere, Daniel Callahan is more explicitly communitarian in his rejection of individualistic autonomy. In the Introduction to his anthology, The Roots of Bioethics: Health, Progress, Technology, Death, he says of himself:

Early on, I was unfriendly to the excessive dominance of the concept of autonomy in the emerging field and, as an alternative, was drawn to communitarianism as the antidote. I believed the hegemony of autonomy thinned the substance of ethics down to a brittle skeleton, demanding too little of us in our personal lives and insubstantial if given too much weight in policy decisions. Someone once called me an “autonomy basher,” and that was a fair charge. Communitarianism is by no means a very precise notion, but it does offer a societal counterpoint to the individualism of autonomy.²¹


²⁰ Parks, Jennifer. No Place Like Home?: Feminist Ethics and Home Health Care, 37.

Callahan thus opts for a more robust focus on the forms of social cooperation that undergird provision of health care. In his 2003 essay “Individual Good and Common Good: A Communitarian Approach to Bioethics”, Callahan argues against liberal individualism, or the idea that each person is a discrete entity fundamentally defined by the freedom to choose. This view ends up steering our attention away from important questions about the shared human good and how to facilitate it through policy. We ought instead to practice skills of rationality, imagination, and insight in order to make comprehensive judgments about what is in our shared best interest. Although he claims liberal individualism is too thin to guide us in this moral objective, it is nevertheless an important part of our cultural history and can be used to refine considerations of the common good.

I accept Callahan’s criticism that liberal individualism does not fully address the kinds of supportive alliances needed to generate self-respect and agency. It would be similarly impossible to practice skills of rationality, imagination, without a threshold level of support from specific others and groups. Yet, comprehensive judgments about what is in our shared best interest have a history, and it is important to critically and continually consider their origin and applicability. Harkening back to an idealized form of cooperation is unlikely to show us the state of actual interactions as they unfold in both the health care system and social and political life in general.

I affirm here and throughout this project that we should not assume that forms of social cooperation always do undergird the reality of health care provision, even if the ideal relationship of care is a cooperative one. There must be a relational network for the possibility of care, but many groups of patients including people with chronic illness must carefully navigate a

---

healthcare system with a history of racism and sexism among other forms of injustice. Aging people, people of size, and people of differing ability levels are unnecessarily pathologized and demeaned. Cissexist norms about gender identity can mean that practitioners will mistreat trans and gender nonconforming patients. Acknowledging these nonideal realities is an essential step toward developing supportive alliances and ensuring that care providers are in fact cooperating with patients. It is impossible to cooperate without first establishing relationships of trust which lead to self-respect and agency, and which in turn make cooperation possible.

Furthermore, even within a system characterized by intersecting forms of injustice, I want to maintain the morally salient possibility that members of different groups could establish trust and respect. I do not want to foreclose on this ideal despite beginning from a nonideal standpoint in my assessment of operations within the health care system. There is also difference between the ways people might collaborate to resist various forms of social oppression and the potential for collaboration among specific care providers and patients. For example, it is possible to have a good working alliance with a practitioner despite the context of social injustice. However, I maintain that practitioners are more likely to establish a good working alliance with patients if they are sensitive to social injustice.

Granted, communitarian authors are trying to correct what they see as an overemphasis on individualism, where self-identity, interests, and choices are conceptually separable from the experience of giving and receiving care.²³ But the health care system as we know it evolved as much from the need to diagnose and manage suffering people as it did to control human suffering in more beneficent ways. The communitarian approach presents perhaps the best case scenario for a chronically ill person or for someone who provides their care; but we cannot infer

²³ Ibid., 8.
a network of cooperative relationships from the existence of a social collective, nor can we assume that groups members are authentically engaged in constructive collaboration simply on the basis of their membership. For example, direct care workers may be employed by an institution or service organization but experience a lack of support from these entities, leading them to feel abandoned on the job. It would be problematic to take these workers as a paradigmatic cooperative ideal when they face exploitation and abuse themselves. Likewise, it is far more likely that older, chronically ill care recipients will have limited ability to pay for care, and may be forced to settle for neglectful or even abusive treatment. I find that the communitarian affirmation of cooperation around shared social goods with respect to chronic and end of life care tends to gloss over these realities.

Jennings, Callahan and Caplan’s point in not that embodiment or social life is necessarily empowering, however. Their claim is rather that positive forms of interdependency characteristic of chronic care provision are more of an ideal for health care provision than the voluntaristic, contractual model of the autonomy paradigm, and I agree with them on this point. But unless these ideals are implemented with greater attentiveness to the oppression faced by chronically ill people and their caregivers, communitarian approaches may not hold much promise for these groups. In order to salvage the more positive aspects of the communitarian notion of interdependency, section three of this chapter will present Kathryn Abrams’ theory of agency, which I believe to be a more appropriate starting point for understanding cooperative relationships. Section four will rely on Hilde Lindemann’s account of narrative repair to clarify how agents with damaged self-respect can restore their agency. More specifically, I am to address how these agents might cope with interrelated harms of deprivation of opportunity and infiltrated consciousness.
If liberal individualism is objectionable because it insufficiently acknowledges the alliances needed for essential human capacities such as reason, it seems libertarian approaches would only intensify this inadequacy. Yet, I aim to avoid dismissing their arguments without exploration, especially given that libertarians such as Tristram Engelhardt productively problematize collaboration around resources such as health care. They also take what I find to be a more accurate view of social interaction, which is characterized more by the clash of competing value systems than by mutual recognition or cooperation. The next section will examine Engelhardt’s critique of the right to health care and his argument against relying on principles such as autonomy in bioethics.


My concern in the previous section was that the communitarian view relies too much on an idealized account of the relationships in chronic care provision. In this chapter, I will explore some opposing views articulated by Tristram Engelhardt: that there is not a basic right to health care discoverable in experience, and that many people receive health care as moral strangers who do not share the values of health care institutions or their caregivers. Engelhardt takes society to lack a common moral fabric, and proceeds to argue on this basis that the apparent applicability of a principle such as autonomy will depend on the importance that principle already has within a culturally specific value system. While Engelhardt’s description of social life and how people navigate the health care system has some persuasive aspects, I find his critique of the application of principles to reduce or even deny the possibility of reflective reconsideration of received meaning. This capacity is not only important for generating agreement about how to apply

---


25 Ibid., 41.
principles such as autonomy, but also for critique and resistance of oppressive norm schemes. The latter is absolutely essential if we are to bolster the agency of older and chronically ill people, along with those who most directly care for them.

Rights-based accounts of autonomy such as liberalism and libertarianism tend to endorse the view that there is a single individual who is the bearer of various rights, and they are free to claim them in any circumstance. As a reaction to the paternalism of the early 20th century, this response made strategic sense: one way to put power back in the hands of patients was to assert their right to receive information about their diagnosis and treatment options, and to make decisions about their care. Questions about whether people have a right to health care in general also became a topic of philosophical interest in the 1970s and 80s. In fact, the Journal of Medicine and Philosophy devoted an issue to the right to health care in 1979.

In his introduction to this issue, entitled “Rights to Health Care: A Critical Appraisal”, Engelhardt defines basic rights as the rights which result from the foundation of a community.26 For Engelhardt, the right to health care is not a basic right: if a right to health care exists, it is invented as much as it is discovered.27 Discussions of rights to health care require an account of the ownership of resources.28 Owners of health care resources have the right to withhold these resources, even though their exercising this right could be morally objectionable.29

Where the communitarian view emphasizes morally admirable forms of cooperation, Engelhardt’s libertarian view does not take it for granted that such cooperation around providing health care resources will ever happen. It is entirely possible to have a community where

---

27 Ibid., 115.
28 Ibid., 116.
29 Ibid.
members do not have access to health care, or where adequate care is too expensive for many citizens to obtain. The U.S. is perhaps already in that situation as insurance costs increase and patients are confronted with surprise bills they cannot hope to repay. It could be doubted that such a social collective is in fact a community, although it may still be worth focusing on successful instances of cooperation as the communitarian authors do. We ought nevertheless to acknowledge that the more common scenario is that health care institutions and the organizations that fund them are profit-driven, and are not necessarily transparent about how they will provide care resources—especially in chronic care situations. It is still largely on the public to hold these authorities accountable and make the case that withholding health care resources is morally blameworthy.

For Engelhardt, the public is not comprised of citizens who share a common moral fabric. In his view, the Enlightenment failed to establish a universally shared set of values regarding what it is to live a good life: “[i]n the failure of reason and in the absence of faith, secular morality is the morality of moral strangers who find themselves bound together and separated by their choices.”30 With a frustrating nostalgia for societies which were supposedly cohesive, he claims that there was once a taken-for-granted sense of moral propriety which did generate a shared fabric and social structure of moral commitments.31 The recognition of multicultural diversity entails that if ethics is the expression of cultural values, ethics must be understood as plural.32

31 Ibid., 33.
32 Ibid.
Without sharing Engelhardt’s lament about the dissolution of taken-for-granted moral sensibility, or the idea that societies were ever truly morally homogenous, Engelhardt is nevertheless correct in pointing out that there exist equally valid expressions of cultural values and this complicates health care provision. This state of affairs does not absolve health care institutions of their responsibility to respect and accommodate value systems which may be different from the pervasive technology-driven acute approach, however. Patients and care providers are tasked with creating and sustaining a mutual understanding of disease, and coming up with effective ways to cope with suffering. It behooves those seeking care to establish a moral friendship with their provider, because patients often do enter the health care system as moral strangers who don’t necessarily share its values. This characterization is more representative of how diverse groups of patients encounter the health care system; yet, the health care system is still responsible for collaborating with them to promote their wellbeing in ways that respect their agency, personhood, and boundaries. Considering the undue suffering imposed on older and chronically ill people during the pandemic, it seems clear that health care institutions had not been effectively collaborating with them before health crises drove them to emergency rooms. A kind of estrangement was then intensified by isolation protocol and the exclusions of friends and family from the bedside. I will discuss the way the health care system can hold on to life at the expense of quality of life in greater detail in Chapter five, which argues for the value of advance care planning.

Engelhardt maintains throughout The Foundations of Bioethics that middle level principles such as autonomy will not resolve conflicts or forge ethical consensus among disparate value systems. Yet, he takes moral conflicts that rest on different social contexts to be harder to resolve than they typically are. Even to distinguish between a consensus that merely
generates norms of political correctness and one which is the genuine expression of the moral values of a particular group would require some insight into a given social context and the ability to make judgments about the origins of norms and values. Engelhardt is nevertheless pessimistic about the possibility of making these retroactive judgments, and claims that any content-full morality will necessarily beg the question.\textsuperscript{33}

In other words, Engelhardt believes that any time we justify the importance of a value or principle in resolving a moral conflict, we have already endorsed that value as significant prior to engaging in justification. For example, considering whether a 28-year-old quadriplegic should be permitted to end his life, appealing to the principle of autonomy could justify different courses of action depending on the understanding of autonomy involved.\textsuperscript{34} If autonomy refers to someone’s right to “be in authority over themselves” this competent individual should be permitted to end his life when he chooses with any help available to him.\textsuperscript{35} If autonomy is understood as a means to liberty that should guarantee a free range of choices, granting him an early death would unjustly restrict his options and may even merit coercive restraint.\textsuperscript{36} So, although principles can be helpful in resolving moral controversies among those with similar moral sentiments but different theoretical approaches, they do not allow people with different moral visions to understand opposing points of view according to Engelhardt.\textsuperscript{37}

Appealing to competing definitions of autonomy probably would not bridge the gulf between persons who held such radically different views about the meaning of the principle. But

\textsuperscript{33} Ibid., 41.
\textsuperscript{34} Ibid.
\textsuperscript{35} Ibid., 58.
\textsuperscript{36} Ibid.
\textsuperscript{37} Ibid.
it seems unlikely in practice that the bearers of these views would be wholly unable to scrutinize and reflect on what aspects of their view best refers to the situation at hand, or try to persuade one another to a view about what values are most at stake. Context and agency are prior to the application of principles, and we have the capacity to reflect on principles and reengage them in a way that Engelhardt dismisses as redundant. I would characterize this operation as the reflective reconsideration of received meaning. Returning to the 28 year old quadriplegic man, there is already widespread agreement by health care and legal institutions that support for mental health and assistance with activities of daily living are important goods, and a general consensus that ensuring access to these should come before allowing someone to end their life. This potential consensus is not sufficient justification in and of itself, but it is still possible to think through the values at stake and justify a course of action. Supposing someone did receive these important forms of support, we could examine someone’s justification for suicide on the basis of autonomy without dismissing it as redundant because it employs a particular way of understanding autonomy as a concept. It is hard to imagine such radically different life worlds that every attempt to compare values and value systems would fail. It is entirely possible to begin from the claim that fair distribution involves ensuring that each person has access to various social goods (one understanding of autonomy), and then concede that once this condition is met, we ought to allow them to direct their lives as they so choose (another understanding of autonomy). Complete value homogeneity is not necessary to engage in this reflective comparison, and homogeneity is likely a projective idealization of certain cultural groups if it exists at all.

---

38 This could unfold rationally, rhetorically, etc., but would be illegitimate if it unfolded coercively. I am not as committed to rational discourse as I am to accurate consideration of context, balanced agency between interlocutors, and prioritizing the agency of the person whose interests are at stake.
Engelhardt holds that authority is ultimately the standards set by those who choose to collaborate, and if this is to be more than just coercion, generating agreement is important. Large scale states must then act as neutral vehicles for spanning particular moral communities, and it is the latter which are responsible for meaning in life and content-full morality. From a grand scale perspective, Engelhardt is right to characterize health care institutions as collaborations among resource-holders in a given society. Institutions are more successful when they can accommodate different value systems and provide basic goods to the diverse groups which comprise American society. But the possibility of these groups advocating for their needs hinges on their already having a certain threshold level of support and recognition. Marginalized groups such as older adults and chronically ill persons cannot meaningfully participate in agreement-generating discourse without recognition and support. Meanwhile, identity formation in relational context closes off not just opportunities for some people, but even more basic forms of self-awareness and critical consciousness necessary for agency. Finding a community where one can engage in content-full moral experience is much more complicated than Engelhardt acknowledges, even if he is otherwise right to claim that authority is the consensus of those in power, and that considerations of a right to health care cannot escape an analysis of who holds what resources.

These practical barriers indicate that support for agency is needed before we can begin to conceive of persons as discrete bearers of individual rights, although I have yet to introduce and explain the concept of agency I take to be relevant to this project. The next section will focus on the distinction Kathryn Abrams proposes between autonomy and agency. She begins with some

39 Ibid., 69.
40 Ibid., 74.
of the limitations of liberal approaches to autonomy, addressing how persons are constituted (and reconstituted) by social experience and group interaction. Abrams is clearer about the problem that groups such as women and older people have their agency cut down before and throughout their efforts to advocate for themselves in society and with respect to their care.

**Liberal Autonomy Vs. Political Agency**

In the previous section, I claimed that it is possible to reflectively compare different concepts of autonomy and consider which one most applies to a situation without begging the question. Engelhardt, once again, claims that the success of a reflective justification means that one has already endorsed the version of autonomy (or any other principle) as valuable before engaging in said justification. Yet, the very possibility of rational persuasion would seem to involve this operation; meanwhile, homogeneity in our definition of values may not be achievable or even desirable. Nevertheless, it is important to conceptualize autonomy with adequate respect for ethical pluralism, and in light of the problem that society is also characterized by oppression and exploitation; manufacturing consensus as often as it generates cooperative, beneficial agreements. Section one discussed the rise of the autonomy paradigm, which employs an individualistic notion of personhood to the detriment of chronically ill people.\(^{41}\) For communitarian thinkers, autonomy should thus be reconfigured as the achievement of selves who are socially embedded and physically embodied, a capacity which grows from the physician-patient relationship rather than presiding over it.\(^{42}\) I am concerned this view skims the best-case-scenario off the top of care relations which are often not acknowledged. At the same time, it does not consider the more internal, psychological agency a chronically ill person would

\(^{41}\) Jennings, Bruce, Daniel Callahan and Arthur Caplan. “Ethical Challenges of Chronic Illness,” 8.

\(^{42}\) Ibid., 17.
need to advocate for themselves in the process of receiving care. Engelhardt rightly acknowledges the social problem that the right to care has to be justified in the context of resources, and the issue that authorities are no more than collectives who have decided to agree. But, his assertion that any content-full morality begs the question needlessly cuts off the possibility of reflective engagement with lived context and how values grow from experience.

In this section, I will explain and adopt Kathryn Abrams’ distinction between autonomy and agency, with the aim of demonstrating how socio-political agency underlies autonomy. A concept of agency is significant for empowering older, chronically ill people because it highlights the kinds of alliances needed to help them avoid needless suffering and an intolerable decline process. I suspect that communitarians and libertarians might both accept that socio-political factors condition the possibility of autonomy, but neither fully articulates the cultural context in which this process unfolds. Both are vague about how gendered, racialized aspects of identity formation can both impede and enhance agency, which is the dynamic that leads to autonomous action or decision-making. Abrams’ explicitly political, collective approach to agency is an important precondition for autonomy—which I also accept to be a relational construct as well as a principle discernable in experience. Thus, Abrams’ account of agency should begin to fill in the ambiguities about how to form valuable, supportive care alliances which cannot be assumed or taken for granted.

Like many contemporary theorists of relational autonomy, Abrams rejects individualist assumptions and describes a pervasive, plural constitution of the subject which unfolds in the context of intersecting power inequalities. Specifically, she agrees with criticisms that the traditional liberal self is assumed to be formed prior to social interaction, not fundamentally
shaped by group membership, and always capable of autonomous choice.\textsuperscript{43} Even more recent accounts of the autonomous self, such as those proposed by Joel Feinberg and Gerald Dworkin tend to focus on an individual’s luck in a way that is more about external constraints or influences rather than how internal expectations impact possibilities for action and engagement.\textsuperscript{44} The political context of dominant group hegemony is a better starting point for understanding dimensions of freedom and constraint, Abrams argues, and there is a collective dimension to the exercise of autonomy that even feminist thinkers have not fully developed.\textsuperscript{45} For this reason, she argues that agency more accurately describes persons’ self-determination, which entails both self-reflection and collective action and can be directed at the cultural and political as well as the individual level.\textsuperscript{46}

There are two key processes for agency according to Abrams: self-definition and self-direction. Each operates in a collective, political context. I will address self-definition first, and then explain what she means by self-direction and how it is distinct from the liberal understanding of self-directed action.\textsuperscript{47} There are three key differences between agency as self-definition and the liberal value of autonomy. First, agency must operate within and in relation to socialization. There is no possibility of transcending socially conditioned visions of the self, but it is possible to “affirm, reinterpret, resist or partially replace them.”\textsuperscript{48} Furthermore, there is a

\textsuperscript{43} Abrams, K. “From Autonomy to Agency: Feminist Perspectives on Self-Direction,” 807.

\textsuperscript{44} Ibid., 810.

\textsuperscript{45} Ibid., 822.

\textsuperscript{46} Ibid.

\textsuperscript{47} I am assuming that “self-determination” would be a more general term which encompasses moments of “self-definition” and “self-direction”, although Abrams never makes this claim explicitly.

\textsuperscript{48} Ibid., 825.
political dimension to the process of recognizing and reflecting on the influence of social norms. Sexist norms do not simply interfere with a positive self-conception for women, for example. Sexist norms condition a host of negative self-conceptions which interfere with women’s ability to take part in satisfying activities and projects: a process which has debilitating returns.

Norms regarding older and chronically ill people operate similarly: developing agency is partly about resisting negative stereotypes and patterns of discrimination, but it involves an additional dimension of reflecting on how these problems can compound damage done to people’s more basic selfhood and capacities. Both gestures are important for oppressed groups such as older and chronically ill adults to be able to maintain self-respect and agency, even if the older person in question needs help in their self-reflection process. Allies who are sensitive to the pressures and challenges faced by these groups are a key part of the second aspect of agency as self-determination. Returning to my concerns in section one, we cannot take it for granted that social groups are characterized by these kinds of alliances, or that they already function well in various parts of the health care system. It is important to consider who can provide the necessary psycho-social support for older people so that they can make competent decisions about their care, which will then be treated with credibility by health care providers. This is among the responsibilities of the health care system, an issue I will discuss in more detail in the subsequent section.

Finally, self-definition is a collective process even though it involves some degree of self-reflection. Generating an appropriate self-image requires engagement in a collectivity. For members of oppressed groups such as aging and chronically ill persons, it is important to engage with others who can challenge pernicious and debilitating stereotypes and affirm more empowering self-definitions. This process requires more than solitary self-reflection or the
occasional conversation with a supportive friend: the kind of conversation that promotes agency involves sharing reactions to structural oppression, supporting one’s allies, and finding ways to challenge those practices that interfere with each person’s potential for self-respect.

There are also key differences between agency as self-direction and the account of self-directed action provided by liberal autonomy. Abrams does not explicitly argue that self-definition is prior to self-direction in the foundation of agency, although one might assume these processes unfold simultaneously. In general, liberal autonomy defines self-direction as identifying particular goals and constructing a plan for one’s life. Self-directed agency places more emphasis on recognizing how social influence may have legitimately or illegitimately led a person to endorse some goals as meaningful. This is different from individuals’ simply being influenced, because barriers to self-direction more typically emerge as a part of a larger system of social and political inequality. Ultimately, collective resistance to politically based barriers to self-direction is a key part of agency.

An account of agency such as Abrams’ can provide a valuable critical framework that fills in what is underacknowledged in the communitarian approach. Callahan once again, suggests that we ought to focus on the forms of cooperation that make trust and respect possible, since these are what condition the possibility for good health care provision among diverse socio-cultural groups.\(^49\) Agency, once again, has to start from the recognition of the hegemony of dominant social groups and the order this imposes. I would add that most groups of people must work to build mutual trust and respect in order to resist a system which is structured to exploit or ignore them. Despite differences in socio-economic status, older and chronically ill people face distinct forms of marginalization which render their choices and preferences less credible or

worthy of respect. Supporting agency in end of life care would entail acknowledging this reality and realigning people and resources so that no one is subjected to neglect or overtreatment against their interests. This might be accomplished with an alternative approach to advance care planning, as I will argue throughout this project.

Abrams affirms the value of engaging with alternative collectivities in order to generate a more empowering self-image and restore damaged self-worth. Such engagement may not allow someone to transcend debilitating socially conditioned versions of themselves, but it “…does allow them greater room in which to affirm, reinterpret, resist or partially replace them.” But how precisely does someone make these important, agentic gestures? How specifically do identity and agency influence one another to make resistance possible? I will thus move to consider Hilde Lindemann’s concept of narrative repair to clarify some of the psychological mechanisms that make agency possible in oppressive social contexts.

**Agency and Narrative Repair**

Abrams’ article “From Autonomy to Agency” was published in 1998, and shares concerns about identity, agency, and resistance to oppressive social constructs with Hilde Lindemann’s 2001 book *Damaged Identities, Narrative Repair*. These examples of feminist scholarship of the late 90s and early 2000s inherit earlier feminist critiques of relational autonomy, and share a desire to better understand how resistance groups and countercultural engagement make agency possible. In *Damaged Identities, Narrative Repair*, Lindemann develops her concept of the “counterstory”: “a story that resists an oppressive identity an attempts to replace it with one that commands respect.”

---


This section will examine the treatment of identity and agency Lindemann offers in this book, and adopt the concept of counterstories as a valuable psychological tool for repairing agency. Yet, Lindemann does not require that counterstories achieve political success, holding more to the idea that they are ethically desirable.\(^5\) I will agree that counterstories can be ethically worthy without achieving political success, but will argue against Lindemann that concrete, material changes in status or resources are nevertheless important for agency and the possibility of autonomy. Where Lindemann confines counterstories’ success to solely empirical analysis, I will conclude by claiming their political impact is still an ethical issue, from which point I will segue to the importance of an externalist criterion for agency.

Once again, counterstories are meant to restore self-respect and agency to those agents whose capacity for them has been damaged by various forms of oppression.\(^5\) First, Lindemann defines identity as the interaction between a person’s self-conception and how others conceive of them.\(^5\) This encapsulates a range of perspectives: from those imposed by relatives, friends, and acquaintances with varying degrees of closeness to those imposed by society at large. Thus, the individual in question is always engaged in process of accepting or resisting these conceptions as they live out their identity over time in social and political context. Identity for both Lindemann and Abrams is a dynamic construct. A counterstory allows a person to resist detrimental identity constructs imposed on them by others.

The counterstory opposes itself to various “master narratives”, which are “the stories found lying about in our culture that serve as summaries of socially shared understandings.”\(^5\)

\(^5\) Lindemann, Hilde. *Damaged Identities, Narrative Repair*, 52.

\(^5\) Ibid., 6.

\(^5\) Ibid.

\(^5\) Ibid.
These are often archetypal, consisting of stock plots and character tropes that allow us to interpret our experiences and justify our actions.\textsuperscript{56} They are not always oppressive, but many of them rely on racist and sexist (and I would add cissexist) narrative strains.\textsuperscript{57} Many counterstories operate in two steps: first by identifying what parts of the master narrative are at work in the construction of an oppressive identity, then by retelling the story about the group or individual to make apparent the morally relevant detail suppressed or misrepresented by the master narrative.\textsuperscript{58}

In sum, counterstories are narrative interventions typically told within communities of choice, are stories of moral (as opposed to nonmoral) self-definition, and are developed to respond to the twin harms of deprivation of opportunity and infiltrated consciousness.\textsuperscript{59} I will briefly explain these three characteristics in what follows. Similar to Abrams, Lindemann’s account of individual agency rests on collective resistance to disempowering dominant norms.

Drawing from Marilyn Friedman, Lindemann contrasts “found communities” into which we are born or find ourselves inadvertently with “chosen communities” which we enter through voluntary association and where we undertake projects related to the reconstitution of our subjective identities.\textsuperscript{60} Chosen communities aren’t always connected to a pro-social or social justice agenda, however. Technically white supremacist groups are chosen communities.\textsuperscript{61} Thus,

\textsuperscript{56} Ibid.
\textsuperscript{57} Ibid., 7.
\textsuperscript{58} Ibid.
\textsuperscript{59} Ibid., 9.
\textsuperscript{60} Ibid.
\textsuperscript{61} Ibid.
counterstories should also involve at least weak or strong moral self-definition which responds to oppression generated by a master narrative.\textsuperscript{62}

Lastly, counterstories are meant to challenge the dual harms of deprivation of opportunity and infiltrated consciousness. Deprivation of opportunity is one way that agency can be damaged, and this has internal psychological dimensions as well as external socio-political ones.

In brief, Lindemann argues that “the control condition”, or how well someone is able to act willfully and reflectively regulate their will is one component of free agency.\textsuperscript{63} “Normative competence” is the other component, and this includes both (1) one’s capacity to understand moral norms and act in ways that demonstrate this understanding, and (2) the ability of others to see that agent’s actions as those of a morally responsible person.\textsuperscript{64} Given that an agent may anticipate the dominant culture’s rejection or defamation of their effort to actualize their moral point of view, this account offers a more nuanced psychological picture of how opportunity can be deprived even before a person tries to act. The degree to which an agent’s consciousness is “infiltrated” refers to her ability to see herself as morally trustworthy or able to be responsible for acting on her moral convictions.\textsuperscript{65} Infiltrated consciousness addresses the problem that when agents lose confidence in others’ ability to see them as a morally responsible person, they are less likely to see themselves as morally responsible persons.

Much as it would seem that a counterstory’s capacity to reinterpret and critique pernicious effects of master narratives would be directly oriented toward resisting oppression,
this is not their goal according to Lindemann.\textsuperscript{66} Instead, they are meant to reidentify oppressed persons as worthy of respect and thus restore their agency.\textsuperscript{67} Whether these agents go on to challenge oppression or not does not diminish the moral act of engaging in narrative resistance for Lindemann.

Finally, master narratives have four defining features I would like to highlight. Lindemann explains in her final chapter on counterstories that master narratives dominate and shape culture thanks to the fact that they are organic ensembles that incorporate and make new references to available constructs and concepts.\textsuperscript{68} They are also sufficiently omnipresent that they shape people’s world view and capacity to understand themselves.\textsuperscript{69} They assimilate resistance through techniques such as victim-blaming\textsuperscript{70} and demeaning opposing viewpoints as part of a lunatic fringe instead of a viable challenge from within.\textsuperscript{71} Finally, master narratives engage in epistemic rigging: a process of circumventing resistance where the certain features of identity constructed and produced by the system are marked in ways than undermine the credibility of anyone exemplifying these features.\textsuperscript{72}

Also in this final chapter, Lindemann distinguishes between a counterstory which is well designed for the task of narrative repair, and a counterstory which is optimally successful.\textsuperscript{73} The

\textsuperscript{66} Ibid., 34.
\textsuperscript{67} Ibid.
\textsuperscript{68} Ibid., 158.
\textsuperscript{69} Ibid., 159.
\textsuperscript{70} Ibid., 160.
\textsuperscript{71} Ibid., 162.
\textsuperscript{72} Ibid.
\textsuperscript{73} Ibid., 151.
optimally successful counterstory will be “culturally digestible” and “widely circulated”; taken up not just by those who struggle with abuse, but also by those who benefit from abusive power arrangements. If a counterstory is optimally successful, people in the dominant group should be moved to reject the master narrative even if they “lose privileges, services, or cherished ways of thinking by doing so.” Conversely, those whose identities were damaged by the master narrative must come to accept the counterstory as identity-constituting. While the political success of a counterstory doesn’t determine its moral value, Lindemann claims that the question of what makes a counterstory politically successful is an empirical matter; a question for sociologists, psychologists, and other social scientists, but ultimately outside the scope of her work.

Returning to the practical claims of this project, I argue that older and chronically ill adults are often struggling against a debilitating master narrative that casts them as frail and unworthy of respect. It would be beneficial to construct communities of choice dedicated to helping them live their last days well and avoiding exploitation and abuse. Health care institutions could recognize the need for these collectivities, and consider ways to provide supportive resources. Although the obligation to support someone’s agency is role-related and context-specific, notions I will elaborate upon in the following chapter, there are still functional changes that would better acknowledge the agentic underpinning needed for autonomous decision making. Greater investiture in advance care planning would be among helpful tools in this regard.

74 Ibid.
75 Ibid. 151.
76 Ibid.
77 Ibid.
Conclusion: The Moral Value of Counterstories’ Political Success and an Externalist Criterion

I respect the right of an author to determine the scope of her inquiry, but the features of a counterstory that make it politically successful could still have a place in ethics, and I disagree that these should be relegated to empirical science alone. A counterstory that results in concrete, material changes in status or resources is of powerful moral benefit to those who have been systematically prevented from obtaining their fair share. Alternately, supposing the empirical source of detrimental master narratives is uncovered by multiple counterstories, social justice would seem to involve taking steps to delegitimize both the narratives and their sources. Generalizing about the arrangements that make a counterstory “optimally successful” ought to be a moral theoretical effort in its own right, with priority given to those narratives that both restored self-respect agency as well as redistributed resources more justly. Redistribution of resources in accordance with repairing agency would give the intervention of the counterstory greater strength and power.

In the article “Personal Autonomy, Social Identity and Oppressive Social Contexts” Rebekah Johnston notes that many theories of agency and autonomy fall under the “damage model”: an approach which tends to focus on how harms done to socially subordinated identities impacts the capacity for autonomy.78 This is often part of an internalist theory: a theory devoted to understanding whether an agent’s motives, choices, and actions are autonomous on grounds which are internal to their moral psychology or lived experiences.79 Externalist theories, on the other hand, do not discount the importance of internal factors but maintain that they are

79 Ibid.
insufficient for determining autonomy.\textsuperscript{80} External factors also have bearing on whether an action or decision is autonomous for Johnston. These include how closely the person in question must live among others who are permitted to harass, profile, exclude and otherwise abuse him.\textsuperscript{81} How these others are allowed to behave puts a constraint on his capacity for autonomy, and diminishes his agency.

Although the optimally successful counterstory will move those unjustly empowered by a master narrative to give up their privileges, whether or not this occurs is almost rendered irrelevant by Lindemann because of the value she places on the internal repair of self-respect and agency. Reassigning moral value to the political impact of a counterstory would, in my view, direct us to a worthy external criterion for both agency and autonomy: that of how closely an agent has to cooperate among those groups or individuals empowered to mistreat him. This condition will be of deep practical significance to people with compromised agency who must navigate the world of chronic care, as well as to direct care providers whose agency may also be under threat. Giving moral consideration to the political context of counterstories, along with addressing realities of who is allowed to control others in potentially oppressive ways would help to facilitate the kind of agency that can make way for autonomous choices and actions.

\textsuperscript{80} Ibid.

\textsuperscript{81} Ibid.
CHAPTER THREE

AGENCY, OBLIGATION, AND AUTONOMY

Introduction

The previous chapter concerned agency: how to understand it as an evolving social and political construct and how to repair it with counterstories in the face of oppressive master narratives. But how and when are we required to support the agency of specific other people? What entities or relational connections are sufficient enough to require that someone ought to support someone else’s agency; particularly throughout the dying process? This chapter elucidates the relationship between agency and obligation, and considers Agnieszka Jaworska’s proposal that the care and value-based inclinations of people suffering from diminished autonomy should nevertheless warrant deference. While I appreciate the respect Jaworska extends to marginalized agents, I find Hilde Lindemann is right to critique this approach. Alternatively, Lindemann proposes that the obligation to support someone’s agency is role-related, and that sometimes we have the duty to persuade loved ones to take actions in the service of their wellbeing. Dying well in accordance with one’s reflectively endorsed values may be too great a task for any lone individual, she notes.¹ Thus, we may have a role-related obligation to “hold” significant others in the values they affirmed when they had fuller agency. This is a duty that we must balance with the need to help them minimize their suffering.²


² Ibid.
As much as it might seem that a closer collaboration between medicine and public health would enable a caring network to hold their loved one through the dying process, I argue in section two of this Chapter that this is not the case. Institutions are required to help people achieve appropriate death just as much as they are required to provide effective medical treatments, but they should not be obligated to require people to comply with public health initiatives. Even ACP should not be obligatory, although it is arguably among beneficial public health initiatives. Health care institutions have a lesser duty to persuade people of the value of these initiatives. Meanwhile, the responsibility to evaluate the worth of any initiative and help the person they care for make good decisions about the value of their participation lies with partners, friends, and relatives. Furthermore, overzealous practitioners and institutions can cause needless suffering when they violate patient confidentiality and privacy more generally.

The final section of this Chapter considers Quill Kukla’s critique of autonomy as a punctuate moment of self-determination. Rather, autonomy should be understood as a set of ongoing practices that involves legitimate placements of trust in medical authorities and thus a displacement of individual decision making.\(^3\) This formula is unobjectionable prima facie; however, Kukla does not discuss the history and context which would lead many marginalized groups to want to protect themselves from medical professionals. Barbara Ehrenreich raises concerns about the socioeconomic position of medicine in her book *Natural Causes*, and these should impact how we aim to “hold” agency of the people we care for.

**What is Owed to Those Who Cannot Care for Themselves: Compromised Autonomy and the Duty to Persuade**

In her chapter entitled “Caring, Minimal Autonomy and the Limits of Liberalism” Agnieska Jaworska introduces the claim that we ought to respect the cares of agents who may

---

\(^3\) Kukla, Quill. “Conscientious Autonomy: Displacing Decisions in Health Care,” 43.
not be able to meet traditional liberal standards for self-governance. Jaworska defines liberal autonomy as the idea that a person’s choices and actions ought not be interfered with so long as they are competent and do not stand to harm anyone else.4 She notes that on the liberal account, it is the “capacity” for autonomy that warrants non-interference, and not necessarily the exercise of autonomy itself.5 However, the kind of harm that may occur as a result of respecting these choices is more expansive than Jaworska seems to admit, not just for the agent in question, but for those who care for them professionally or in more familiar ways. This section will introduce Jaworska’s argument for respecting the cares of minimally autonomous agents, and consider Hilde Lindemann’s counterargument in the chapter “What and When to Let Go: Identities at End of Life” from her 2014 book *Holding and Letting Go: The Social Practice of Personal Identities*. Lindemann argues in favor of a duty to protect which ought to supersede deference to the cares and values of minimally autonomous agents. I concur, and add that failures of appropriate role-related duties are in fact harms with greater societal implications. This claim is consistent with liberal standards for autonomy, but gestures toward a greater responsibility for agency than liberalism acknowledges.

Jaworska begins her argument by discussing the case of a terminally ill man who nevertheless opts for surgery, a case initially introduced by Atul Gawande. Although Gawande discusses this case in an early article, it is also a key part of the introduction to his 2013 book *Being Mortal*. I will retrace the case details as Gawande presents them in this text, pages 3-6. Lazaroff was a former city administrator who had lost his wife and had grown accustomed to living alone. He developed a malignant form of cancer which caused him to fall several times

---

5 Ibid.
and require around-the-clock morphine to control his pain. His son, David, moved into his home to care for him. Gawande and his other doctors explained to him that the metastasis of his cancer was compressing his spinal cord, and his lower body was becoming paralyzed. He could choose to undergo surgery, but even that would only allow him to live for a few more months. Lazaroff chooses the surgery, telling David “[d]on’t you give up on me…[y]ou give me every chance I’ve got.” According to Gawande, Lazaroff’s operation was a technical success, but his condition quickly worsened. He died in exactly the way he had not wanted to die: restrained and sedated, on a ventilator, “…with tubes in every natural orifice and several new ones.” Gawande regrets allowing his patient to die this way, and indicates that physicians ought to be permitted to act paternalistically in these kinds of cases.

Jaworska is concerned about the precedent Gawande is setting with this example, and argues that choosing contrary to one’s values and preferences does not necessarily mean the choice is not autonomous or worthy of deference. The requirements of what makes a choice autonomous are not as demanding as liberalism tends to assume, she argues. Jaworska introduces three criteria for choices which meet a standard of “minimal autonomy” and which warrant nonintervention at a minimum. First, the attitude which motivates the choice should be internal to the agent: it should represent some aspect of their self. Philosophical accounts of internality, for example those by Watson and Frankfurt, often require that agents be able to step back from their primary motivations and participate in self-reflective evaluation of their

---

7 Ibid., 87.
8 Ibid., 88.
9 Ibid.
desires.\textsuperscript{10} For Jaworska, motivational hierarchy and evaluation are not necessary for someone to have an authentic representation of themselves in something they care about.\textsuperscript{11} For example, she notes that children as young as two or three demonstrate genuinely self-regarding cares about people in their lives and other features of their experience even though they cannot reflectively evaluate their motives.\textsuperscript{12} Jaworska does not necessarily claim that this criterion alone is sufficient to warrant deference, but this kind of internality is a plausible foundation for her second criterion of self-governance.\textsuperscript{13}

Jaworska’s second criterion, self-governance, entails minimally that the agent acts on the basis of reasons.\textsuperscript{14} Motivational hierarchy and reflective evaluation are also not necessary for self-governance: someone does not have to deem the motive good in order to act on it, or for other to see why they acted as they did.\textsuperscript{15} Teenagers, for example, play pranks without necessarily deciding that mischief is good; and others could still recognize the internally endorsed care which motivated their action.\textsuperscript{16} Jaworska’s third criterion is mental freedom, which involves not being beholden to emotions such as fear, jealousy, or despair—all of which hijack our ordinary ability to identify self-regarding cares and find reasons for acting on them.\textsuperscript{17} It is important that the person in question avoids being in the grip of one potential reason and is

\textsuperscript{10} Ibid., 89.
\textsuperscript{11} Ibid., 90.
\textsuperscript{12} Ibid.
\textsuperscript{13} Ibid., 93.
\textsuperscript{14} Ibid., 93.
\textsuperscript{15} Ibid.
\textsuperscript{16} Ibid.
\textsuperscript{17} Ibid., 95.
open to the possibility of seeing things otherwise. This once again does not involve full reflective evaluation of potential reasons. It is sufficient that the person is prepared to question their current reasoning and be prepared to modify it in the face of more compelling reasons.

Returning to Gawande’s Lazaroff case, Jaworska aims to make space for the possibility that Lazaroff’s decision could be minimally autonomous: that it could be the authentic expression of a care. She initially suggests that we might interpret Lazaroff’s commitment to a good (or non-interventionist) death becoming overwhelmed by fear and led him to request more treatment at any cost against his deepest convictions. Jaworska maintains that we ought to respect his decision to undergo surgery if it did meet the three criteria she establishes. In other words, if staying alive was a genuinely internal care which rose to the surface of Lazaroff’s motives, and he reasonably endorsed a course of action potentially allowing him to forestall death, and he was not in the grip of potentially hijacking emotions and could have seen things otherwise, we ought to accept his decision as autonomous. Jaworska’s point throughout is that it is easier to exercise autonomy than we tend to assume because the higher-level cognitive abilities needed for motivational hierarchy or evaluative judgment are not necessary for someone to have a care that warrants deference or non-intervention.

However, it seems that this respect or deference nevertheless demands a great deal from everyone involved in Lazaroff’s medical treatment as well as his life in general. His relational network will feel the impact of his choices. Lazaroff is likely to subject his care team and his son (at a minimum) to a phenomenon bioethicists describe as moral distress. Patricia Pendry defines

---

18 Ibid., 96.
19 Ibid., 98.
20 Ibid., 86.
21 Ibid., 99.
moral distress as the physical or emotional suffering that is experienced when internal or external constraints prevent someone from taking the course of action which they believe to be right.\(^{22}\) If they are forced to abide by Lazaroff’s minimally autonomous choice, Dr. Gawande and David would assuredly suffer significant moral distress. In my view, this does constitute the sort of harm to others which liberalism counts as a potential reason to intervene, but there are reasons beyond liberalism’s harm principle not to permit Lazaroff to make this choice. As Hilde Lindemann points out, dying well in accordance with one’s reflectively endorsed values may be too great a task for any lone individual.\(^{23}\)

In an earlier article, “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value”, Jaworska argues that having a sense of one’s life as a whole and rational decision-making capacity are also not necessary preconditions for making autonomous choices.\(^{24}\) To add to her previous assertions: people could choose autonomously without the capacity to step back from their primary motivations, nor do they need to participate in self-reflective evaluation of their desires; \textit{and} they can lack a sense of their lives as a whole along with the capacity to make rational decisions. None of these capacities are needed for someone to make autonomous decisions which warrant deference and nonintervention. In this earlier article, she is critiquing Ronald Dworkin, who argues in \textit{Life’s Dominion} that a sense of one’s life as a whole and rational decision making are essential capacities for autonomy.\(^{25}\) Dworkin also makes a distinction between critical interests which derive from a person’s values, and experiential

\(^{22}\) Pendry, Patricia. “Moral Distress: Recognizing it to Retain Nurses,” 217.


\(^{25}\) Dworkin, Ronald. \textit{Life’s Dominion}, 218-37.
interests which concern a person’s more passing states of mind.\textsuperscript{26} Jaworska aims to broaden the category of critical interests on the grounds that the values involved often do express someone’s concern with something fully independent of themselves, which is more significant that desiring or wishing.\textsuperscript{27} Valuing is sufficient for autonomous decision-making according to Jaworska. It has three essential features: the person thinks they are correct in wanting what they want, achieving this want is tied to their self-worth, and the importance of fulfilling this want is seen as good in and of itself, independent from the person’s experience.\textsuperscript{28}

Jaworska offers several examples of how granting value-based choices would work with people who are actually suffering from Alzheimer’s, a few of which I would like to highlight.\textsuperscript{29} First, Mrs. D. had moderate to severe dementia, and was unable to name the day of the week, the month, the season, year, city, and county she was in, underestimated her age, and had difficulty finding her way to the bathroom at the care center she attended two days a week. Yet, she was able to participate in activities that accorded to her values, often volunteering as a research subject for tests and experiments at the NIH. In her own estimation, she could have declined participating, but she wanted to contribute and help her fellow human beings. Similarly, Dr. B, an Alzheimer’s patient who scored even lower on cognitive tests, also valued participating in research studies. He specifically wanted to contribute to the advancement of science, a desire seemingly consistent with his values when he was healthy. In comparison to other group activities, participating in the studies had an especially positive impact on his pride and self-worth.

\textsuperscript{26} Ibid., 230.


\textsuperscript{28} Ibid.

\textsuperscript{29} The Mrs. D and Dr. B examples are on pgs. 117-118 of this article.
The strength of Jaworska’s argument regarding the worth of valuing depends at least in part on the previously established credibility of these organizations and initiatives. It is less objectionable to allow an impaired elder to participate in non-invasive behavioral studies conducted through the NIH, especially if it contributed to their feelings of self-worth. But, suppose instead that the studies they valued participating in could adversely impact their mental health, or cause them unanticipated trauma. Worse, their values could justify participating in political rallies with white supremacist leanings, or the desire to become involved in what many might consider to be a cult. Jaworska’s final specification about valuing, that the importance of fulfilling this want is seen as good in and of itself, independent from the person’s experience, seems to lack a subject. Who is it that views the action as good in and of itself? It cannot be the agent themselves, or it would fail to be independent from their experience. How much social consensus would then be needed for the activity or choice to count as good? It has become clear in recent years that Americans are increasingly willing to support right-wing white supremacist groups and leaders, who might say of their projects that they are restoring some “good” against growing “false” consciousness of social injustice. Supposing one’s aging parents suffered from dementia, or were even just poorly informed, one would undoubtedly feel responsible if they were taken in by misrepresentations of this nature.

My focus on questions of agency in the previous chapter is relevant here as well. I appreciate that Jaworska aims to expand the scope of respect we should have for the choices and preferences of people coping with dementia, but her position commits people in the agent’s relational network to equally objectionable forms of deference. It is also unclear what is owed to marginally autonomous people who are choosing on the basis of a value or care. It would be preferable to begin by examining the agency or relative empowerment of these agents in their
lives. It is worth questioning whether they have the alliances and support needed to give their consent, or justify their actions. Beginning with a focus on agency would point us in the appropriate direction for ascertaining what we owe to marginalized agents, and how to offer them the support needed for making fully autonomous choices even when they are in decline. Such an approach would not necessarily have to lapse into paternalism if it had adequate respect for each person’s unique experience, relational network, and social situation.

Jaworska offers another example of a dementia sufferer who chooses on the basis of his values. In this case, Mr. Burke has a more moderate form of the disease, and is able to take care of his basic needs and get around on his own.\(^30\) One day, he arrives at home thrilled to have purchased a new red pickup at a local dealership. He has always wanted a truck like this, although he and his wife had already agreed they were not prepared to make the sacrifices to their budget that would allow them to afford it. In an attempt to help them sort out their situation, their doctor asks about Mr. Burke’s decision. “A man needs his truck,” Mr. Burke explains. He is fulfilling a long-standing desire for this important status symbol, and claims he can afford it. Later on, Jaworska interprets Mr. Burke’s declaration as expressing an ideal, a standard by which to judge himself (although he did not necessarily arrive at this ideal via an assessment of the trajectory of his life).\(^31\) She does not necessarily specify that Mr. Burke should be allowed to keep the truck, but we might assume that she believes his choice was made on the basis of his values and that he ought to keep it despite the consequences. We might also expect that Mr. Burke’s decision would meet the three criteria for a caring attitude Jaworska discusses in her 2009 chapter: that the decision to buy the truck was sufficiently internal to Mr. Burke, that he

\(^30\) The Mr. Burke example is on pg. 107 of: Jaworska, Agnieszka. “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value.”

\(^31\) Ibid., 119.
had appropriate self-governance, and had adequate mental freedom and was not in the grip of hijacking emotions.

In the text *Holding and Letting Go: The Social Practice of Personal Identities*, Hilde Lindemann presents an alternative perspective regarding how we ought to treat the choices of marginalized agents.\(^{32}\) For Lindemann, it is not only permissible, but sometimes morally incumbent to intervene paternalistically to keep someone from proceeding with a foolish choice.\(^{33}\) Especially for children and people with cognitive impairments, there is a duty to protect which ought to supersede deference to the cares of minimally autonomous agents.\(^{34}\) In Mr. Burke’s case, it would be appropriate for the doctor to refer the Burkes to a social worker who could help Mr. Burke have some access to the vehicle he values without putting his wife in financial jeopardy or subjecting other drivers to a potentially impaired motorist. Lindemann also argues that if minimally autonomous agents were once more fully autonomous, the values they professed and endorsed at this stage should have a greater claim to respect than what they care about in the present.\(^{35}\) “Particularly if their choice is self-destructive,” she argues “…those nearest to them can have role-related responsibilities to coerce them into acting in accordance

---

\(^{32}\) A recent article by Kit Rempala et al builds from Jaworska’s assertion that the cares and/or values of marginalized agents ought to be respected to endorse Lindemann’s claim that we are required to “hold” marginalized agents in their identities (Rempala, Kit, et al. “Holding On: A Community Approach to Autonomy in Dementia.” Loyola eCommons., 2). These two positions are incompatible, aside from the issue that Lindemann explicitly rejects Jaworska’s argument. These authors also claim that Lindemann’s view of personhood as a dynamic interpersonal construct (which I address in Ch. 5 of this project) could serve as a ground for Jaworska’s view that a marginalized agent’s values are sufficient enough to warrant deference (Ibid., 2-3). This is not the case. The relational network of the marginalized valuer would be obligated to persuade them from making superficial choices against their more deeply held values according to Lindemann.


\(^{34}\) Ibid., 190

\(^{35}\) Ibid., 182.
with their reflectively endorsed values.”36 It would be worth consulting with Mrs. Burke about her husband’s choice, and offering her some support given that she has a role-related obligation to help her spouse avoid bankruptcy along with potential homelessness or a motor vehicle accident. It is implausible that she would be indifferent to these outcomes, and unfair to ask her to defer to her husband’s shallow preferences.

Particularly with respect to end of life decision making, I would agree with Lindemann that the preferences someone articulated when they were at the fullest point in their agency should carry greater weight. Though, it is difficult to balance this with concerns about a person’s present wellbeing and potential to suffer. Lindemann also comments on Gawande’s Lazaroff example, and notes that suffering is valuable or worthless exactly according to what it buys us, and that how deeply a value has entered into our identity matters with respect to how much someone will suffer.37 Supposing Lazaroff had a deeply held religious conviction against stopping treatment and considered it a form of suicide, and then suddenly opted for a more peaceful death, David should try to persuade him to stay true to his original belief system.38 For Lindemann, whether the duty to protect someone from suffering should take priority over the duty to hold someone in their identity depends on how strong a critical interest someone has in preserving their life.39 Granted, it might be countered that everyone has a critical interest in preserving their life; but she is making this claim in reference to the issue that some people have deeply held convictions against what they would consider to be suicide, and that going against these convictions would impose a kind of suffering that goes beyond physical pain.

36 Ibid.
37 Ibid., 191.
38 Ibid.
39 Ibid.
Yet, this difficult balancing situation could potentially be avoided by prioritizing concerns about each persons’ agency. A practical consequence of such a focus could be greater support for the advance care planning process, whereby trained planners guide each person to think through and share their more deeply held values about how they want their lives to end. Currently, no role of health care practitioner is obligated to engage in ACP, and dying people are essentially at the mercy of their nuclear families and immediate care providers to hold them in their identities through the ambiguity of decline. I will explain more of Lindemann’s concept of holding in Chapter five “Why Practice ACP: A Case for Holding”. At this point in the project, I hope it suffices to say that specific others have a duty to support the agency of their partners, friends, and caring relatives. It is also important that the health care system practice sensitivity toward the shifting relational dynamics that undergird patients’ agency. At the risk of stating the obvious, providing access to medical care and helping people avoid intolerable suffering in the dying process are responsibilities of the health care system. However, it may not be incumbent on institutions or society at large to persuade specific persons to take measures which may or may not contribute to their diminishing wellbeing; especially if these measures amount to worthless surveillance and the call to participate proceeds on the basis of surface community membership.

**Threats to Agency in Context: What is Required of Health Care Institutions and Public Health Agencies**

Throughout her consideration of marginalized autonomy, Jaworska seems motivated by the concern that the value laden choices of persons with dementia will not receive adequate respect. But perhaps what persons with marginal autonomy are owed is that the others who care for them will hold them in their identities, persuade them in favor of their more deeply held values, or guide them in ways that allow them to avoid suffering. Yet, at this juncture, the notion
of obligation I aim to invoke still requires clarification. I have noted that spouses, friends, and relatives are required to support agency by holding their loved ones in their identities. Especially given that agency is bound up with communities of choice, as I argued in the previous chapter, it is also important for networks of allies to construct the counterstories that enable those they care for to live in authentically self-determining ways.

This chapter will address the responsibilities of larger groups such as health care institutions, and attempt to specify what measures should be required of them in the service of health promotion and the avoidance of suffering. Institutions are required to help people achieve appropriate deaths just as much as they are required to provide effective medical treatments, as I argue in Chapter one. However, they are not obligated to require people to comply with public health initiatives; nor should they have power to impose a care regimen upon those who refuse it. Health care institutions have a lesser duty to persuade people of the value of these initiatives, while one’s partners, friends, and relatives are more obligated to evaluate the worth of any initiative and help the person they care for make good decisions about the value of their participation.

Granted, advance care planning is a health care initiative in and of itself, and institutions are responsible for ensuring that people have access to it. As I argued in the previous chapter, it is important not to assume that communities are comprised of cooperative relationships which work to bolster everyone’s agency and wellbeing. Health care institutions will be more successful to the extent that they provide care and treatment measures in response to the needs and desires of the diverse groups they serve. These needs and desires include privacy and the

---

40 Dr. Parks and I have noted before in discussion that no one really argues in favor of forcing treatment. Since I’ve now agreed with Lindemann that we have a duty to protect loved ones from potentially self-harming behaviors and choices, I want to emphasize that this should involve persuasion; not coercion.
capacity to control one’s associations and affairs. Institutions must be able to navigate between the extremes of overzealous engagement and neglect, making space for closer interpersonal alliances among persons to work in ways that foster agency and wellbeing. Persuading a loved one to make healthy choices can be valuable, but it is complicated by the fact that older adults informally report that what they most value is their ability to control their own affairs, their freedom to maintain relationships of their choosing, and their privacy.

Thus, this section will begin by discussing the harm of the “total institution” whereby an authority takes control away from people to manage their own affairs, schedules and relationships. Although this kind of structure would seem to contribute to an institution’s capacity to provide uniform care for all and for staff to operate on a predictable schedule, it also interferes with the agency of older people; many of whom dread not being able to reflect upon or control what they will do each day. Again, I suspect this threat may have motivated Jaworska’s call for respecting the cares and values of marginalized agents; however, I find Lindemann has the stronger claim in these kinds of cases. If someone’s agency has dwindled to the point where they cannot care or choose for themselves, then those who care for them have a role-related responsibility to guide (but not force) them toward activities which will prevent suffering and safeguard wellbeing. Thus, deliberations about how much intervention marginalized agents need operate best when they happen among trusted spouses, friends, relatives, immediate caregivers, and potentially even doctors supposing the person in question has built a trusting relationship with one. The people who comprise the agent’s support system are those who can best hold them in their identities and help them participate in meaningful activities despite decline.

Furthermore, health care providers can inflict a serious disservice to their patients’ agency and wellbeing when they make assumptions about who is involved in their network of
support, or when they involve other persons or entities in their care against their wishes. Atul Gawande claims in Being Mortal that medicine’s “job” is to “…enable well-being,” and elsewhere that closer collaboration between medicine and public health would be of benefit to diverse cultures and nations. I am concerned that Gawande’s approach would lead to institutional overreach: health care institutions and public agencies can perpetuate harm and injustice by tracking and surveilling people even if they are required to extend benefits and attempt to prevent suffering. No one should be required to participate in ACP, for example. The approaches to ACP I critique in section three of chapter one all stood to fail because they misapprehended the relational configurations which provide people with adequate support to consider and communicate their end of life care preferences. Trust had not necessarily been built among those meant to facilitate ACP and those being encouraged to participate. With respect to health initiatives, it is the more intimate network of people who aim to hold the personhood of marginalized agents who should persuade them on the grounds of what will preserve meaning in their lives and help them to avoid suffering. Once these configurations of holding are operational, people are better able to navigate the health care system in ways that meet their needs and avoid violating their boundaries.

The threat of the “total institution” as well as the more familiar threat of neglect are each very real for aging and chronically ill persons. The term “total institution” was coined by

---

41 I accept the possibility that health care providers could also have some helpful insight into a patient’s relational life. They might be able to identify and work around abusive relatives or spouses, and help connect their patients with other providers or services that would benefit them. However, the possibility that a patient has a personal relationship with their health care provider is less likely now more than ever before, and the harm that can be done by institutional and professional overreach is salient.


sociologist Erving Goffman in his 1961 book *Asylums*.\(^{44}\) Comparing nursing homes with the prison system, Goffman noted that total institutions break down the barriers that separate the different spheres in which we ordinarily live our lives.\(^{45}\) There are four main characteristics of the total institution: all aspects of life are carried out in the same location under the same authority, daily activities are carried out in groups where members are expected to do the same activity in unison, activities are tightly scheduled under the authority of institution officials, and activities are brought together into one plan designed to fulfil the official aims of the institution.\(^{46}\)

In *Being Mortal*, Atul Gawande introduces the idea of the total institution to illustrate one kind of harm that results from a failure to confront human decline. Instead of avoiding thinking about death, we ought to think through the kinds of activities that create meaning in life for people whose agency is dwindling, he argues.\(^{47}\) A crucial component of this is having a degree of control over one’s daily life and privacy. Gawande describes the experience of an older woman, who voluntarily moves in to a nursing home fearing for her safety after falling twice in a week.\(^{48}\) Once a resident, she found she was deeply unhappy—although the official aim of the institution was “caring”, her experience no longer felt like living.\(^{49}\) Another nursing home resident, Alice, relays to Dr. Gawande that the things she missed most were “…her friendships, privacy, and a


\(^{45}\) Ibid.

\(^{46}\) Ibid., 74.

\(^{47}\) Ibid., 77.

\(^{48}\) Ibid.

\(^{49}\) Ibid.
purpose to her days.”\textsuperscript{50} Gawande notes that “[i]n every nursing home and assisted living facility, battles rage over the priorities and values people are supposed to live by.”\textsuperscript{51} Some residents like Alice resist through noncooperation: refusing scheduled activities or medication.\textsuperscript{52} Nursing home staff appreciate some of these “fighters” who show “dignity and self-esteem”, at least until these traits interfere with institutional priorities and they must intervene.\textsuperscript{53}

Given that health care institutions typically have power over their residents, it seems as though this is what Jaworska aims to avoid with her argument in favor of respecting the cares of dementia sufferers. It would appear to be ethically desirable and in the service of their agency for caregivers or family members to respect their immediate cares and not pressure them to go along with purportedly health promoting activities. On the surface, it may seem like a gesture of respect not to try to challenge misguided belief systems they may have; and, practically speaking, there may not be opportunities to reach someone when they are in moments of lucidity. It is important to consider how much an impaired loved one will suffer, physically and in the sense of their self-respect and agency and then gauge what kind of holding or letting go\textsuperscript{54} is appropriate for them. Thus, I find that Lindemann has the stronger claim in these kinds of cases: if someone’s agency has dwindled to the point where they cannot care or choose for themselves,

\textsuperscript{50} Ibid., 75.
\textsuperscript{51} Ibid.
\textsuperscript{52} Ibid.
\textsuperscript{53} Ibid., 76.
\textsuperscript{54} I will explain these ideas of Lindemann’s in more detail in Chapter five “Why Practice ACP: A Case for Holding”, and illustrate how they are at work in the dying process in Chapter six “A Very Easy Death: Recognition and Letting Go at End of Life”.

then those who care for them have a role-related responsibility to guide (but not force) them toward activities which will prevent suffering and safeguard wellbeing.

A more intimate understanding of a loved one’s character and preferences is often helpful in this regard, but so is the kind of expertise developed by direct caregivers whose work is geared toward helping people manage their activities of daily living and find ways to participate in meaningful pursuits despite potential impairment. I will develop this idea more thoroughly in Chapter seven, “Care Workers as Care Planners”. Although it would be a conflict of interest for a care worker to conduct end of life care planning with someone they are actively caring for, their acumen situates them to ask the right kinds of questions should they retrain as ACP facilitators. It is also possible that a care worker may develop a “fictive kin” relationship with a client, and could be included in ACP discussions if this is amenable to the client and their network of alliances.

Throughout Being Mortal, Gawande shares examples of tragic instances where potentially dying people, along with their partners and relatives, suffer unjustly thanks to poor institutional design and a general failure to accept decline and death. He is sensitive about the problem that it can be convenient to institutionalize people who could live more fulfilling lives under different social arrangements. However, it can be challenging to attribute concrete responsibilities to specific others, whether these are family members, friends, communities or institutions. Like Jennings, Caplan, and Callahan, Gawande seems inclined to attribute responsibility for caring for older and chronically ill people beyond families and doctors, presumably to the community at large.
Meanwhile, medicine is not simply about ensuring people’s agency and self-directedness for Gawande: medicine’s “job” is to “…enable well-being.”55 This is a potentially admirable but frustratingly ambiguous claim. One would need insight into specific interactions to determine whether nursing home staff who restrain disoriented, potentially combative residents are protecting their wellbeing or contravening their agency.56 Being Mortal explores various historical successes and failures of respect for human decline, but does not necessarily arrive at a method for attributing specific responsibilities to concrete others. As elusive as such a method might seem, it is important to identify who might be responsible for supporting the agency of dying people, and how community organizations and social institutions might factor in.

Gawande does extoll one approach in the 2021 New Yorker article “The Costa Rica Model”, but his practical proposals tend to rely on an idealized account of community participation for their success. Life expectancy is often indexed to national income, Gawande notes, but Costa Rica has emerged as an exception to this tendency.57 Although Costa Rica’s per capita income is only a sixth of that of the United States, health care costs are a fraction of ours, and life expectancy is approximately 81 years to the U.S.’s 79.58 Costa Rica has accomplished this by making public health measures aimed at the health of the population as a whole central to the delivery of medical care.59 Gawande claims that the COVID-19 pandemic has revealed the impoverished state of public health even in affluent countries, and believes that closer

55 Ibid., 259.

56 Although there is widespread agreement among care providers that chemical or physical restraints should be used only as a last resort.


58 Ibid.

59 Ibid.
collaboration between medicine and public health would be of benefit to diverse cultures and nations. The approach to public health Gawande describes in this article relies heavily on culturally specific values which Americans tend not to share. Arguably, many Americans would trade a few years of life expectancy for privacy, the right to limit who surveilles them, and the capacity to control their daily lives.

The structure of Costa Rica’s approach to public health is not fully objectionable in and of itself. First, it allowed public health officials to collaborate with hospitals and clinics to set objectives for the health care system as a whole. Second, it worked to combine data about household conditions and needs with the medical record system, and use the aggregate data to guide priorities, set targets and track progress. Supposing this data is sufficiently de-identified, this is not necessarily problematic. Tracking progress would need to be similarly respectful of the privacy and anonymity of specific persons or groups. Finally, each citizen would be assigned to a local primary health care team called an EBAIS (Equipo Básico de Atención Integral en Salud), which would include a doctor, a nurse, and a community health worker. These community health workers have both the skills of a medical worker and a public health aide, and they are responsible for conducting home visits to every person in their district.

Gawande shadows a community health worker and a doctor in their engagements with the community, and essentially all of the people they interact with welcome their attention. No one is suspicious, and no one sends the community health workers away. In one instance, a

60 Ibid.
61 Ibid., 35.
62 Ibid.
63 Ibid.
64 Ibid., 36.
doctor has a telehealth appointment with a woman suffering from diabetes and severe hypertension who claims she has been waiting for over a year for follow-up blood tests. The doctor writes a new order for the tests, and advises her to come to the office to pick them up. Realizing she has “failed” to do that before, he decides to send the order home to her with a neighbor coming to the clinic later that day. It seems a fair generalization that most Americans would balk at this approach: who would want their neighbor to know about potentially sensitive health conditions like diabetes or hypertension? Unless there is a previously established trusting relationship with that neighbor and this is well documented in a patient’s chart, this is a violation of privacy. Furthermore, perhaps this patient’s avoidance is an act of indirect resistance. She may not want to tell the doctor directly that she doesn’t want the test and is willing to risk the consequences.

Gawande would likely reply that American values about privacy and control are at odds with our well-being; perhaps even our very survival. But this claim seems to conflict with his previous critique of the ways we deprive older adults of control over their daily lives, and the way we ought to be sensitive to their needs and boundaries. The Costa Rican model of public health succeeded because collaborative relationships within Costa Rican communities were already strong. As I argue in Chapter two, we cannot take it for granted that these alliances are

---
65 Ibid., 38.
66 Ibid.
67 Ibid.
68 I am arguing this doctor was wrong to involve a neighbor in this patient’s care without her knowledge or consent. Yet, I argued in the previous section that it would be beneficial for Dr. Burke’s doctor to refer him and his wife to a social worker, whether he consents or not. This is in part because we know that Mr. Burke’s decisional capacity is compromised, and his choice to get the truck could render he and his wife bankrupt and homeless, aside from potentially endangering other motorists. There are risks to others that warrant intervention in this case, whereas if this woman chooses not to proceed with testing or treatment we have no reason to suspect she cannot reasonably decide for herself.
extant or functioning in any given society or culture. Trust between health care providers and communities has to be built, and success hinges on how well providers understand the history, character, and needs of the diverse groups they aim to serve.

In section one, I argued that attribution of care responsibilities should begin from consideration of a person’s agency, focusing on whether marginalized agents have the capacities and alliances needed for participating in meaningful actions and activities. Lindemann proposes once again that the loved ones who are involved in holding someone through their dying process should consider the potential for suffering involved in each course of action (or in not acting). People suffer when they feel their boundaries are not respected, and when they feel they lack control over their social lives and day to day affairs.

Thus, I reject Gawande’s claims that medicine should be the part of society most responsible for enabling people’s wellbeing, and that medicine and public health should collaborate more closely in ways which more readily impact people’s daily lives. Even otherwise healthy people opt for a minimum of intervention as often and for as long as possible; although they value medical treatment once they need it. The complex judgments required to determine what would give a potentially dying person meaning in their last days are not within the scope of public health, although successful public health initiatives should still work to provide access to basic services. Medicine can be of some help thanks to its ability to predict what kinds of treatments might help someone manage pain or preserve lucidity, but once this information is shared, it should be up to the person and their caring network to deliberate about how to proceed. It is not the responsibility of medical or public health professionals to involve

---

69 At the same time, medical and public health authorities are in the wrong if they recommend activities or treatments which fail to contribute to the health of the people and communities they aim to serve. They can also be neglectful, a problem exacerbated by the tendency not to fund them. Suppose they wrongly determine a disaster site is safe, for example. In these cases, they have failed in a basic but general responsibility.
neighbors, family members, or even other caregivers unless the person in question is at imminent risk. Even then, practitioners should be sensitive about whom to involve. A person’s agency is actively harmed when authorities decide or assume who comprises their network of support.

**Trust and the Displacement of Individual Medical Decision-Making**

In the previous section, I argue that health care institutions and public health agencies should not be required to track or enforce the individual participation of any person. It is not the responsibility of medical or public authorities to help someone build connections or thrive in their community, although it is not objectionable if they happen to do so. To the extent that they try to do this in insensitive ways, they risk violating the privacy and personhood of patients. Support for agency should come from one’s alliances, whether these are friends, relatives, or partners; with social workers and individual clinicians invited in once a person has this support.

In this section, I aim to call into question the idea that access to medical professionals or involvement in health screenings is necessarily agency-preserving. Writing roughly twenty years after Jennings, Caplan and Callahan’s critique of the autonomy paradigm, Quill Kukla is also concerned with bioethics’ tendency to assume the relevant “unit” of autonomy is the punctuate decision: a choice someone makes in isolation from the rest of their health care, and presumably in isolation from the rest of their relational lives. We ought rather to understand health care as a

---

70 I see that this might commit me to something akin to an “anti-vax” position. However, the invasiveness and benefit of each public health intervention is significant, as is the possibility of limiting other forms of institutional participation. Vaccines have well-demonstrated efficacy and do not require much bodily intervention; public health agencies should encourage people to get them. In cases where someone refuses, other measures should be expected of them such as wearing a mask or not participating in large group activities. With respect to vaccines such as those for smallpox, etc., I would still maintain no one should be forced; although it would be fair to exclude them from certain forms of institutional participation.

71 Helping people build alliances in their communities isn’t valueless, however, it is just more properly the role of social work. There exists a different set of limitations regarding how social workers should proceed, but this seems to be a digression for the point I am making about medicine and public health.

72 Kukla, Quill R. “Conscientious Autonomy: Displacing Decisions in Health Care,” 35.
set of ongoing practices that involves legitimate placements of trust in medical authorities and thus a displacement of individual decision making. This formula is not objectionable in and of itself, but Kukla does not discuss the history and context which would lead many older people, women, and people of color to want to protect themselves from medical professionals. Barbara Ehrenreich traces important social and historical injustices in her book *Natural Causes*, and these should impact how we aim to “hold” agency of the people we care for.

In their 2005 article “Conscientious Autonomy: Displacing Decisions in Health Care”, Quill Kukla critiques the idea that autonomy can be measured by considering particular moments of medical decision making. “Underwriting the standard bioethics picture is a strong assumption that the relevant “unit” of autonomy (or lack thereof) is the punctuate decision—a decision made in response to a discrete choice that can be understood in isolation from the rest of the patient’s health care.” The pervasive understanding is as follows: if the person is appropriately informed and competent to make a decision, then their decision meets the standard of autonomy, but this is insufficient and can result in neglect. Instead, we ought to acknowledge that health care practices are ongoing and can involve legitimate placements of trust and thus “displacement” of individual decision making.

Self-determination is not as central to autonomy as Faden, Beauchamp and theorists of informed consent assumed, and it would be preferable to consider whether patients have taken a conscientious responsibility for their health and wellbeing in Kukla’s view. This involves becoming personally committed to health norms as guided by practitioners, and carrying them

---

73 Ibid., 39.
74 Ibid., 35.
75 Ibid., 37.
76 Ibid., 35.
Clinicians should thus acknowledge that they play an authoritative role and use it to foster their patients’ conscientious relationship to health care practices which goes beyond just promoting good health, and can affirm the dignity, respect and integrity of these patients.\textsuperscript{78} There tends to be a greater moral harm committed by practitioners who do not guide their patients toward appropriate health care practices than by those who try to influence their habits and decisions. Promoting autonomy is thus far more consistent with the exercise of medical authority than we tend to imagine, Kukla claims.\textsuperscript{79}

Finally, Kukla acknowledges that not every person will require the same amounts of guidance from health care professionals to be conscientiously autonomous. For conscientious autonomy, “it is not the amount of medical management that determines how respectful a set of practices are, but rather the shape and meaning of those practices.”\textsuperscript{80} Thus it is possible for someone to be “managed” continuously, but in a way that is respectful of their needs and capacities: for example, there are thoroughgoing cognitive and physical therapy regimes for children with Down’s syndrome whose implementation demonstrates respect for their development and independence.\textsuperscript{81} Conversely, people who are HIV positive have reported that abstinence, sterilization and abortion have been proposed as options for them in ways which are not simply neglectful and dismissive, but intrinsically disrespectful of their lives and needs.\textsuperscript{82}

\textsuperscript{77} Ibid.
\textsuperscript{78} Ibid., 43.
\textsuperscript{79} Ibid.
\textsuperscript{80} Ibid.
\textsuperscript{81} Ibid.
\textsuperscript{82} Ibid.
Kukla, once again, argues that clinicians should try to foster their patients’ conscientious participation in health care practices, using their authority to influence patients’ habits and decisions. But how this authority is established matters, as does the socioeconomic position of medicine. Kukla does not acknowledge these factors, which should impact the ways we come to trust clinicians and doctors. Thus, it is worth considering an alternative view proposed by Barbara Ehrenreich in her book *Natural Causes: An Epidemic of Wellness, The Certainty of Dying, and Killing Ourselves to Live Longer*. Herein, Ehrenreich seeks to understand how the quest for control over our bodies and lives is acted out through medical care, the market for diet and exercise-based solutions, and the so-called wellness industry.\(^83\) She provides her own perspective regarding the value of these interventions:

> “Once I realized I was old enough to die, I decided that I was also old enough not to incur any more suffering, annoyance, or boredom in pursuit of a longer life. I eat well, meaning I choose foods that taste good and will stave off hunger for as long as possible, like protein, fiber, and fats. I exercise—not because it will make me live longer but because it feels good when I do. As for medical care: I will seek help for an urgent problem, but I am no longer interested in looking for problems that remain undetectable to me. Ideally, the determination of when one is old enough to die should be a personal decision, based on a judgment of the likely benefits, if any, of medical care and—just as important at a certain age—how we choose to spend the time that remains to us.”\(^84\)

People of all decisional capacities and their supportive networks ought to be making these kinds of judgments about the value of interventions, treatments, and therapies. Meanwhile, it should matter to clinicians if their patient reports that they feel fine. Clinicians have an obligation to help their patients avoid unnecessary, degrading, and costly procedures; it is troubling that many of them prefer not to consider the socioeconomic and sociopolitical issues which impact the delivery of medical care.


\(^84\) Ibid., 3.
Ehrenreich has a well-founded skepticism regarding the benefit of routine medical screenings, particularly for people who may not have much time left to live. This statement of values is compelling, and if it is worth an agent’s holding it for themselves it is worth holding this view on behalf of a loved one. Once she reached the age of fifty, her doctors began to recommend and even plead that she undergo colonoscopies and mammograms. “But if mammography seems like a refined sort of sadism, colonoscopies mimic an actual sexual assault” she objects, given that one is literally drugged and penetrated during a colonoscopy. She put the colonoscopy off year to year, until she realized that any cancerous polyps would be unable to grow fast enough to kill her until she would be close to death from other causes. Against medical advice, Ehrenreich chose in favor of her best interests. It is straightforwardly harmful to subject oneself or one’s loved ones to invasive, degrading tests when the treatment would compromise the possibility of more time to be involved in the activities that give one’s life meaning.

Particularly in the United States, profit is among motivations to test and screen people, Ehrenreich points out. Health care institutions make money by subjecting otherwise healthy patients to tests and evaluations, and the tendency to over test can be intensified by the fact that doctors may have a financial interest in the screening or imaging facility to which they are referring patents. Drug companies also pay for research and offer financial incentives to doctors who test patients for conditions that will result in the prescription of their products.

---

85 Ibid., 7.
86 Ibid.
87 Ibid.
88 Ibid., 9.
89 Ibid., 10.
In another of Ehrenreich’s autobiographical narratives, her primary care physician recommends a bone density scan. When she asks why, he tells her it would be worth knowing if the result was positive and her bones turned out to be hollowed out by age. Fortunately, he replied, there is now a new drug for low bone density; and, think of the alternative, which might well be a hip fracture followed by a rapid descent to the nursing home. Ehrenreich consents to the test on the grounds that it was noninvasive and covered by her insurance. The result was a diagnosis of “osteopenia”, a diagnosis she uncovers is shared by nearly all women over the age of thirty-five. Osteopenia is not a disease so much as it is a normal feature of aging. Routine bone-scanning turned out to have been promoted and subsidized by the drug’s manufacturer. Worse, the favored medication at the time of Ehrenreich’s diagnosis was found to cause some of the problems it purported to prevent, namely bone degeneration and fractures. She reflects that “[a] cynic might conclude that preventative medicine exists to transform people into raw material for a profit-hungry medical-industrial complex.” Whether the motive in question is to prevent suffering or enhance wellbeing, the profit-driven aspect of medicine should factor in to everyone’s deliberations about the worth of diagnostic procedures and treatments.

Ehrenreich’s insight into the socioeconomic context of medicine has important ramifications for trust as well. One might agree with Quill Kukla that health care is a set of ongoing practices which involves placing trust in medical authorities, but it is important to consider the possibility that not all practitioners will be appropriately skeptical about the ways economic factors (such as the drug industry and the health insurance market) impact medicine and the delivery of health care. A more trustworthy practitioner would need to be as

---

90 This narrative can be found in *Natural Causes*, pg. 4
conscientious about these problems as they would expect patients to be conscientious about following treatment plans.

**Conclusion**

Throughout this Chapter, I have recommended that the health care system should practice sensitivity toward the shifting relational dynamics that undergird patients’ agency. There is not necessarily a uniform way to execute this, because groups of patients—throughout the U.S. and internationally—have diverse needs and health priorities. Patients are people first, and they require a certain threshold level of empowerment and support from others in their lives to deliberate about the worthiness of research participation, screenings, and treatments. Especially when someone’s agency is compromised due to dementia, it is important for the people who care for them to “hold” them in their values and do what they can to prevent their suffering.
CHAPTER FOUR
HISTORICAL FAILURES OF ADVANCE CARE PLANNING

Introduction

Although the rise of the autonomy paradigm in the 80s led to greater focus on end of life care preferences than previous decades, there remains a general concern in bioethics that most efforts to create a viable advance care planning system have not been successful. Advance care planning (ACP) is defined by the National Hospice and Palliative Care Organization as “making decisions about the healthcare you would want to receive if you’re facing a medical crisis.”¹ This can include obtaining information regarding treatment, making decisions about which treatments you would or would not want if diagnosed with a serious illness, communicating your values to loved ones, and completing advance directives such as a living will or power of attorney for health care.² Generally speaking, most authors claim that problems in advance care planning are attributable to communication barriers. These barriers occur throughout the web of each person’s relationships: with care providers and physicians, with family members who may or may not serve as surrogate decision-makers, and in the interstices of interactions with medical and legal institutions.


² Ibid.
Despite fears about “death panels” leading up to the passage of the Affordable Care Act, most Americans do want to limit life-extending treatments in old age.\(^3\) Older adults are also more likely to have their preferences respected if they engage in ACP.\(^4\) So, why has it failed to become a standard for quality health care provision? This chapter addresses the reasons why ACP is not necessarily standard practice despite its benefits. First, there is a barrier between clinical practice and the legal procedures required to make care preferences binding on clinicians. The first section of this chapter examines Castillo et al’s identification of five practical barriers which prevent effective planning for end-of-life care. Next, the National Academy of Medicine’s\(^5\) comprehensive report *Dying in America* offers a thorough analysis of both the institutional and interpersonal barriers to a tolerable death. The second section will present evidence concerning two key problems they identify: that confronting mortality is anxiety provoking for patients and their loved ones, which results in avoidance of ACP, and that the fractured organization of the health care system is not conducive to consistent adherence to end of life care preferences.

Finally, ten years after the passage of the Patient Self-Determination Act in 1990, many studies attempted to address why no substantial improvements had been made in advance directive completion. I will address the findings of two of these from 1998: one by Nicholas Christakis and Theodor Iwashyna, and another by Tulsky et al. More recent evidence suggests that medical education concerning end-of-life care had still not improved by 2003, while educational interventions to train healthcare professionals in end-of-life communication improved self-efficacy, they showed no effect on patient-level outcomes as recently as 2016.


\(^4\) Ibid.

\(^5\) At the time of publication, this organization was known as the Institute of Medicine. It is cited as such in the bibliography and throughout the footnotes, but I will refer to it in the body of the Chapter with its current iteration.
Doctors were still coping with a lack of time in 2007, and were still reluctant to discuss end-of-life care without a significantly threatening prognosis in 2010. Legal liability of physicians can also result in the impetus to overtreat, and this accounts for why patient’s requests for comfort measures or limited care may not be respected.

I will not necessarily elaborate on how the COVID-19 pandemic has exacerbated these historical problems given that it was the focus of Chapter one. However, it is evident that each of these problems would be exacerbated by COVID-19. Communications barriers were further compromised by isolation protocol. Meanwhile, crisis standards of care intensified the pressure and time constraints put on all levels of care providers. This Chapter will examine some of the reasons why efforts to establish advance care planning as a standard of care failed well before the pandemic, with a view toward how ACP could be reconfigured to prevent the tragic loss of life in the future.

**The Divide Between Advance Directive Law and Clinical Practice**

In the article “Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care” Lesley Castillo et al argue that there is a fundamental tension between advance directive law and clinical practice. While having discussions about end of life care preferences may alleviate some of the ambiguities faced by surrogate decision makers, legal restrictions and requirements prevent many patients from communicating their preferences in ways that ensure they will be respected by families and care providers. Castillo et al identify five legal and content-related barriers to the effectiveness of advance directives, and propose five corresponding ways the legal system could adapt to help a greater range of patients have a voice.

---


7 Ibid.
in their end of life care. Barriers include poor readability of advance directives, restrictions on who may serve as a surrogate decision maker, execution requirements, inadequate reciprocity among states and institutions, and religious, cultural, and social inadequacies. I will provide a brief summary of each barrier, and proceed to address how these authors propose changing advance directive law.

Advance directives are not easily readable according to Castillo et al, and this keeps patients from understanding their options for care and communicating them to health care providers.\textsuperscript{8} Although most older adults read at a fifth-grade level, the typical advance directive form is written above a twelfth grade level.\textsuperscript{9} Advance directive forms are also not always available in many patients’ native languages, and can contain ambiguous language, such as whether to forgo a treatment if a condition is “terminal” or “irreversible”.\textsuperscript{10} It is not necessarily obvious what these terms might mean to a layperson, and there may be differences in the ways clinicians use them. If patients are unable to understand the options on advance directive forms, this limits their ability to make decisions about their preferences or communicate them in meaningful ways. Health literacy is defined by Title V of the Patient Protection and Affordable Care Act of 2010 as “the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.”\textsuperscript{11} Castillo et al argue that health literacy is what impacts patients’ ability to understand and communicate about the preferences

\textsuperscript{8}Ibid., 122.
\textsuperscript{9} Ibid.
\textsuperscript{10} Ibid.
for end of life care, and this contributes to lower rates of care planning among racial and ethnic minorities.\textsuperscript{12}

Castillo et al also claim that restrictions on who may serve as a surrogate decision maker presents problems for advance care planning. First, they note the exclusion of domestic partners, and then address how other marginalized groups may not have surrogates.\textsuperscript{13} When this article was published in 2011, domestic partners were not allowed to serve as surrogates in all states. However, when the Supreme Court ruled it unconstitutional to deny same-sex couples the right to marry in Obergefell vs. Hodges in 2015, this expanded the range of legally recognized spouses who could serve as surrogate decision makers. Thus, I would argue that barriers related to domestic partnership and surrogacy have been mitigated to some degree since the publication of this article.\textsuperscript{14} Nevertheless, Castillo et al maintain that “[h]omeless, institutionalized, socially isolated, disabled or migratory patients often lack legally appropriate health care agents and prefer to name their trusted case managers, social service providers, or physicians as surrogates.”\textsuperscript{15} This remains a barrier to care planning in that there is no widely-recognized legal process for naming these providers as surrogate decision makers, at least in states where it is legal to do so.

It is also difficult for many patients to meet the execution requirements needed to make an advance directive legal. Most states require the patient include witnesses who are not spouses, relatives, health care providers or employees of a health care provider.\textsuperscript{16} Even if a patient’s

\textsuperscript{13} Ibid.
\textsuperscript{14} And yet, these protections are in jeopardy yet again following the 2022 Supreme Court Dobbs decision.
\textsuperscript{15} Ibid.
\textsuperscript{16} Ibid.
physician documents their verbally expressed wishes, oral advance directives are also not universally recognized.\textsuperscript{17} A clear procedure for substantiating orally-expressed preferences, along with a trained group of persons who can serve as witnesses could make execution requirements less of a barrier. Finally, notary and identification requirements prevent many homeless, migratory, and institutionalized patients from naming surrogates or executing advance directives.\textsuperscript{18}

Castillo et al note that “[r]eciprocity refers to whether an advance directive executed in one state will be accepted in another.”\textsuperscript{19} Although a patient may have adhered to procedures such that their advance directive is legally binding, this is still not a guarantee that it will apply the same way in another state. The language on advance directive forms may differ among states, and there may be differences in interpretation even when comparable legal standards are invoked. For example, someone designated as a durable power of attorney for health care (POAHC) in Massachusetts can legally withdraw artificial nutrition and hydration and consent to long term care facility placement, but in Wisconsin a patient would have to give specific written permission for their POAHC to be able to make these decisions.\textsuperscript{20} Although courts generally agree that out of state advance directives have legal standing, it is still up to clinicians to adhere to them, and when there are conflicts patients must have the “financial, educational, and social means” to hold their physician accountable for following their advance directive.\textsuperscript{21} Nearly all

\begin{itemize}
\item \textsuperscript{17} Ibid.
\item \textsuperscript{18} Ibid., 124.
\item \textsuperscript{19} Ibid.
\item \textsuperscript{20} Ibid.
\item \textsuperscript{21} Ibid.
\end{itemize}
states grant physicians the right to conscientiously object to providing treatment, and only some require that physicians provide a timely referral to another practitioner.\textsuperscript{22}

Finally, Castillo et al point out the religious, cultural, and social inadequacies of advance directives. Most documents presume a single-agent rather than a group or family standard for decision-making, require completion of a written document rather than oral expression, and tend to assume that the patient wants to be aware of their prognosis.\textsuperscript{23} Most advance directive forms also do not acknowledge or accommodate varying religious beliefs about treatment or death rituals, or the preferences of specific groups—such as the preference of isolated older persons to go (or not go) into nursing homes, or the preference of homeless persons to document tattoos or other identifying markers so as to avoid an anonymous death.\textsuperscript{24}

The five ways Castillo et al aim to alleviate these barriers are jointly directed at law and at the healthcare system, and they propose that a relationship and communication-based approach should supplant the current legal-transactional one.\textsuperscript{25} First, we ought to ensure that advance directives are written at a 5\textsuperscript{th} grade level, and then eliminate restrictions on who may serve as a surrogate.\textsuperscript{26} At this point, same-gender couples can marry, which has promoted a more inclusive standard at least to the extent that couples have the means and desire to become legal spouses. It is up to “clinicians” to “direct extensive effort toward helping patients to connect with social networks, distant family, or religious leaders.”\textsuperscript{27} In cases where no potential agent can be

\textsuperscript{22} Ibid., 125.
\textsuperscript{23} Ibid., 124.
\textsuperscript{24} Ibid.
\textsuperscript{25} Ibid., 125.
\textsuperscript{26} Ibid., 126.
\textsuperscript{27} Ibid.
identified, it ought to be legal to appoint a case-worker or other professional who is not directly responsible for providing medical care. Oral and out of state advance directives ought to be accepted with the original specifications in which they were issued, and we ought to eradicate witness and notary requirements. Lastly, documentation of religious, cultural, and social values and goals for treatment should be encouraged—presumably also by clinicians.

While the call for greater flexibility and communication in advance care planning would seem to allow for more patients to think through and express their preferences for care, clinicians would still be tasked with a detailed and sensitive undertaking with respect to some of their patients’ most intimate, perhaps even unconscious preferences. “Clinicians” is also somewhat vague: given that clinical practice is usually led by physicians and higher-level nursing personnel, one might infer these are the persons who should bear responsibility for this new standard of communication, but Castillo et al never make this specification. One might also question whether it is properly the physicians’ responsibility to ascertain who might qualify as a patient’s surrogate and seek them out, or to promote patients’ engagement with social networks, family members or religious leaders. In practice this could be accomplished by a variety of members of the healthcare team. Yet, there is a danger that when communicating with patients and surrogates about end of life values is everyone’s responsibility, such communication risks becoming a task every role of practitioner can ostensibly neglect because no specific person bears responsibility for it. On the other hand, Castillo et al’s legally-oriented interventions seem far more achievable. Simplifying language on advance directive forms, accepting oral and out-

28 Ibid.
29 Ibid.
30 Ibid.
31 Granted, physicians would know applicable laws about who could represent a patient, although determining in practice who will best serve as a patient’s surrogate is more complicated.
of-state advance directives, and eliminating witness and notary requirements could be accomplished by a singular federal mandate. These changes likely would help more people complete valid advance directives, but they do not necessarily help with the more arduous task of considering preferences for end of life care and making arrangements over time that will ensure a tolerable decline. This would seem to require guidance and support over time from someone intimately familiar with the operations of clinical practice.

**Barriers to Successful Advance Care Planning: Patient and Surrogate Hesitancy and Inconsistency of Care**

In the Introduction, I noted the National Hospice and Palliative Care Organization’s definition of advance care planning, which is “making decisions about the healthcare you would want to receive if you’re facing a medical crisis.” This includes obtaining information regarding treatment, making decisions about which treatments you would or would not want if diagnosed with a serious illness, communicating your values to loved ones, and completing advance directives such as a living will or power of attorney for health care. As early as 1997, the National Academy of Medicine report *Approaching Death* drew a useful distinction between advance directives and advance care planning. The term “advance directives” refers to various types of patient-initiated documents such as living wills and durable power of attorney for health care forms. These can be completed at any time and in any state of health that allows one to do so, although the specifications therein would only be binding once someone is terminally ill.

---


33 Ibid.

34 Institute of Medicine. “Dying in America: improving quality and honoring individual preferences near the end of life,” 120.

35 Ibid., 122.
Advance care planning is a much broader concept which could begin at any point in a person’s life, regardless of their state of health, and which can be revisited periodically as their health status changes.\(^\text{36}\) One could conduct advance care planning with any interlocutor in theory, although specifications would be more likely to be followed if they are guided and recorded by a physician, nurse practitioner, or social worker.

Authors such as Charles Sabatino have pointed out that by 2010, debates about the merits of various kinds of advance directives have been supplanted by a focus on the more general approach of advance care planning.\(^\text{37}\) The National Academy of Medicine (NAM) committee responsible for *Approaching Death* also found shortcomings within advance directive documents, but was more optimistic about the potential benefits of advance care planning.\(^\text{38}\) Their comprehensive 2015 update, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* discusses the relatively recent history of America’s concerns about end of life care and delineates some of the reasons efforts to promote advance care planning have not succeeded. In 1997, the NAM found five key shortcomings to the advance directive approach.\(^\text{39}\) These included “patients’ and families’ lack of awareness of or interest in completing forms”, clinicians’ reluctance to adhere to patients’ preferences, barriers to meaningful conversations especially when a patient’s prognosis is uncertain, lack of institutional support or standardized procedures, and “resistance within the medical culture as well as differences in families’ cultural traditions.”\(^\text{40}\) Expanding their analysis to advance care planning

\(^{36}\) Ibid., 120.


\(^{38}\) Institute of Medicine. “Dying in America: improving quality and honoring individual preferences near the end of life,” 120.

\(^{39}\) Ibid., 119.

\(^{40}\) Ibid., 120.
in general, the IOM cites four main reasons in 2015 advance care planning is not yet a norm for health care provision. These include a natural reluctance on the part of patients, clinicians and families to discuss death and dying, a fragmented health care system which makes the discussion of end-of-life preferences “someone else’s problem”, poor quality communication in the conversations that are held (typically in crisis situations), and inadequate structural support for advance care planning, which should include clinician training, payment, and record-keeping.41 This section will present the evidence concerning the first two of these general problems: that confronting mortality is anxiety provoking for patients and their loved ones, which results in avoidance of ACP, and that the fractured organization of the health care system is not conducive to consistent adherence to end of life care preferences. The subsequent section will examine issues related to communication with the health care team and inadequate structural support.

Unsurprisingly, most people do not want to consider how they might die and most healthy adults can avoid thinking about it. People with mild to moderate chronic illness also tend not to want to plan for their decline. In a 2012 California survey of adults of all ages, respondents who had not spoken with a loved one about their wishes at end of life gave reasons including having too many other things to worry about (41 percent), not wanting to think about death or dying (26 percent, cited by 38 percent of Latinos and 26 percent of Asians and Pacific Islanders, but only 15 percent of African Americans and non-Latino whites), and that their family member did not want to discuss it (13 percent).42 In a study of oxygen-dependent COPD patients, the three most common answers to why they would prefer not to discuss their end-of-life care

41 Ibid., 117.
preferences were: (1) “I would rather concentrate on staying alive than talk about death” (75%), (2) “I’m not sure which doctor would be taking care of me if I get very sick” (64%), and (3) “I don’t know what kind of care I would want if I get very sick” (37%).43 Thus, the incentive to ignore the possibility of decline is predictably strong among healthy people as well as those who are coping with chronic illness.

While persons themselves tend to avoid thinking about their own mortality, their potential health care proxies or agents can find advance care planning stressful and may want to avoid being responsible for health care decisions. Especially for spouses or relatives who are already providing care for their loved one, deciding for them can be an additional burden. Significantly, if the person serving as a health care agent had not engaged in thorough discussions regarding end of life preferences, they were typically unable to accurately gauge what their loved one’s preferences would have been.44 Although it would be impossible to ascertain in reality whether a surrogate’s choices aligned with the preferences of a patient once they truly were incapacitated, studies have measured the congruence of hypothetical decision making. A study examining approximately 20,000 patient-surrogate comparisons found that surrogates predicted patients’ treatment preferences with 68% accuracy, and this figure did not correct for the possibility of change agreement.45 While it is possible that surrogates may just be unaware of patients’ preferences or feel that their preferences would change given new information, it is also possible that surrogates may actively choose not to follow the patient’s preferences because “they believe that doing so would result in an immoral, or simply less

Especially in cases where the patient has a preference for non-intervention, it is emotionally difficult for a surrogate to let their loved one potentially suffer or die.

Furthermore, even when someone does agree to serve as a surrogate decision maker, clinicians face obstacles involving them in the patient’s care. In a 2009 survey of 281 physicians regarding their experiences with surrogate decision making, one in five reported difficulty contacting the patients’ potential agent, and one in four reported never having talked to these agents personally. Of these 281, 206 (73%) had made a decision for a patient lacking decisional capacity in the past month. These decisions most typically concerned palliation and hospice (26%), changes in code status (18%) or withdrawal of life sustaining care (18%). To explain in more detail, code status refers to how much intervention a person will receive in a medical emergency. Persons are always assumed to be “full code” unless there are explicit specifications to the contrary, and for any of these to apply, that person would have to be terminally ill or of advanced age. In that case, a patient may be designated a partial code such as do-not-intubate (DNI), which would limit mechanical ventilation but still allow them to receive cardiopulmonary resuscitation (CPR). A do-not-resuscitate order (DNR) is the only way to ensure that CPR is not started and no extraordinary measures such as mechanical ventilation will

---


48 Ibid., 1025.

49 Ibid.

50 https://medical-dictionary.thefreedictionary.com/code+status

51 Ibid.
be applied. Thus, about one in four physicians made crucial decisions about whether a patient should receive palliative care or hospice treatment as opposed to ordinary medical care, while one in five were responsible for such significant decisions as whether to permit or deny CPR.

Inconsistency of care presents another barrier to successful advance care planning. In the current fragmented health care system, it is likely that patients will be engaging with many different clinicians who are unfamiliar with their goals and values. Aside from the problem that clinicians are often unable to contact their patient’s health care agents or access their advance directives or unaware of what the patient would have wanted, there can be judgment conflicts among physicians. There is no legal precedent that would force one physician to defer to another’s judgment, and a patient’s surrogate would have to have the awareness and the means to hold them accountable if they deviated from the patient’s expressed preferences.

To share a personal example, during my internship with a clinical ethicist, one of our patients was a 92 year old man with dementia. Although he was in otherwise tolerable physical health, his family and primary care physician (PCP) had decided to give him an order for DNR given his advanced age and the fact that he no longer had a coherent sense of who and where he was. One of the attending physicians caring for him during his stay in the hospital overturned the DNR order without consulting the patient’s family or the PCP, and it fell to the ethicist to contact the PCP regarding the change. In fact, I am not certain whether the patient’s family was ever made aware of the change in code status and subsequent reversal. Had the ethicist not intervened, the family could have found their father subjected to CPR or mechanical ventilation when there had been discussion, consensus, and appropriate portable documentation of their preferences.

\[52\] Ibid.
In the context of today’s multi-institution healthcare setting, there is further evidence that a patient’s end-of-life care preferences will not be documented in a way that is accessible across care settings. As much as contact details for health care agents can fail to be recorded, patient preferences themselves may fail to become part of the medical record even when they are discussed with providers. In a post-collection study of data from gleaned the Assessing Care of Vulnerable Elders studies, researchers began from the finding that of 245 older people interviewed, 24% reported speaking to their doctor about their decision to limit medical care. Of this quarter of participants, only 22% had any note in their medical chart regarding their preference. Rates of inclusion for advance directives were similarly low: of 164 patients, 66% of whom reported they gave their AD to their physician, only 15% of medical records contained the AD. The accessibility of information about end of life care preferences was particularly compromised when patients transfer between different health care settings: for example, from a long term care facility to the doctor’s office or emergency department. For both the provider office to hospital and provider office to emergency room comparisons, the likelihood that advance care planning documentation would be available was no greater than chance.

Yung at al speculate that their findings reflect both a reluctance to engage in advance care planning discussions as much as a failure to document preferences about end of life care. They suggest a more structured approach such as the Physician Order for Life-Sustaining Treatment


55 Ibid.

56 Ibid., 864.

57 Ibid., 865.

58 Ibid.
(POLST) would be preferable to the current piecemeal approach to ACP. Especially given that frequent care transitions are more likely at end of life, it is important that care providers are aware of significant limitations on treatment options. Otherwise, the care provided risks subjecting patients to painful and expensive treatments they would have preferred to avoid.

**The Persistence of Medicine’s Resistance to Planning for End-of-Life**

Initially, the Patient Protection and Affordable Care Act (ACA) of 2010 contained a provision that would have reimbursed clinicians for the time spent in advance care planning with patients. But, allegations that this would result in “death panels” emerged in 2009, with the result that this provision was left out of the final draft of the ACA. “Death panels” referred to institutional committees whose purpose was to determine who should have access to acute care measures at end of life. The pervasive fear was that the institution, rather than the doctor and care team, would limit access to care resources. 2 years after the passage of the ACA and despite the involvement of medical and health authorities in attempts to counter this misinformation, 36% of Americans believed the ACA does contain a provision to “allow a government panel to make decisions about end-of-life care for people on Medicare”, while 20% were unsure about the law. As time has passed, people have become increasingly misinformed: in 2013 40% believed the law contained this provision, and 21% were unsure. The impact of misinformation about

---

59 Ibid., 866.


61 Ibid., 367.

62 Ibid.

63 Ibid.
“death panels” demonstrates that at least some Americans are primarily concerned with being denied access to intensive care and other acute care measures at end of life.

However, when polled about what they would want in the end, very few Americans would opt for all possible treatment measures. In the 2010 article “Advance Directives and Outcomes of Surrogate Decision Making before Death”, Maria J. Silveira et al measure the association between preferences documented in advance directives with outcomes of surrogate decision making at end of life. They rely on data from survey proxies in the Health and Retirement Study, which focuses on the preferences and outcomes for persons aged 60 or older who had died between 2000 and 2006. Of 3,746 subjects, 42.5 required decision making, while 70.3% lacked decisional capacity and 67.6% had an advance directive. The majority of participants who had a living will requested limited care (92.7%) or comfort measures only (96.2%), whereas only 1.9% requested all care possible. Comparing these preferences with the care people actually receive, the authors found that those who requested less intervention were more likely to receive it, while only about half of those who wanted all care possible received it. Specifically, 83.2% of those who wanted limited care received it, and 97.1 who requested comfort care received it; while of the 10 people who wanted all possible treatment, only 5 received it. In general, those who had either an advance directive or had appointed a POAHC

---

65 Ibid.
66 Ibid.
67 Ibid.
68 Ibid.
were much more likely to indicated a preference for limited treatment, and to have their preference accommodated.\textsuperscript{69}

Another study from 2010, “End-of-Life Discussions, Goal Attainment, and Distress at End-of-Life: Predictors and Outcomes of Receipt of Care Consistent with Preferences” by Jennifer W. Mack et al shows that people are more likely to indicate preferences for limited care or comfort measures only in end-of-life planning, and that for the most part their preferences are respected. Of patients suffering from cancer who participated in the study, 83\% opted to limit treatment options, and “68\% of patients (220 of 325) received EOL care consistent with baseline preferences.\textsuperscript{70} There were more patients who did choose to receive all treatment possible in Mack et al’s study in comparison to Silveira et al’s (17\% to 1.9\%), but they were still in the minority. Patients who opted against life-extending treatments also reported lower levels of physical distress.\textsuperscript{71} Factors that influenced whether care provided was consistent with patients preferences were that the patient recognized they were in fact terminally ill, and had discussed their preferences with their doctor.\textsuperscript{72} Both of these studies show that most Americans do in fact want to limit their care through care planning, and that making efforts to plan for care is more likely to ensure providers comply with patient or surrogate preferences than not engaging in care planning. Despite all of the aforementioned challenges to conducting successful ACP, it does benefit the majority of people on the whole.

\textsuperscript{69} Ibid.

\textsuperscript{70} Mack, J. W., et al “End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences,” 1203.

\textsuperscript{71} Ibid.

\textsuperscript{72} Ibid.
So why then is ACP still not a standard for quality health care? Aside from the divide between clinical and legal practice, hesitation on the part of patients and their agents, and institutional fragmentation, what stands in the way of everyone being able to consider and communicate their wishes about end-of-life care? In 1997’s *Approaching Death*, the NAM cites resistance within the medical culture and clinicians’ reluctance to adhere to patient wishes as shortcomings of the advance directive approach. By 2015, these are replaced by “poor quality communication in the conversations that are held (typically in crisis situations)” and “inadequate structural support for advance care planning, which should include clinician training, payment, and record-keeping.” This final section will examine these problems in more detail, beginning with early evidence that communication between doctors and patients in ACP is insufficient. More recent evidence indicates that doctors are still not well prepared in medical education to conduct ACP, most experience a lack of time to do it well, and many remain reluctant to engage in end-of-life conversations unless the prognosis is bad. Legal liability of physicians can also result in the impetus to overtreat, and this accounts for why patient’s requests for comfort measures or limited care may not be respected.

The Patient Self-Determination Act was passed by Congress in 1990, and was an important step in promoting the value of conversations about end-of-life care preferences and advance directives (ADs). It stipulated that all health care facilities receiving Medicare or Medicaid funding must provide information about ADs, ask patients whether or not they have

---


74 Ibid., 117.

75 Ibid., 121.
one, and incorporate the AD into the medical record. Yet, AD completion rates did not go up over the course of the 90s. Thus, there were several studies in the late 90s geared toward understanding why so few people participated in end-of-life care planning or had advance directives. I will consider two key studies from 1998 which address these issues: Nicholas Christakis and Theodore Iwashyna’s “Attitude and Self-reported Practice Regarding Prognostication in a National Sample of Internists” and Tulsky et al’s “Opening the Black Box: How Do Physicians Communicate About Advance Directives?”. Both show that physicians are hesitant to engage in conversations about end-of-life, and that when they do, the preferences elicited are not especially helpful in placing meaningful limitations on treatment. It might be hoped that these problems were resolved in subsequent years, but medical education had still not improved roughly five years later in 2003, while the effects of educational interventions to train healthcare professionals in end-of-life communication showed no effect on patient-level outcomes as recently as 2016. Doctors were still coping with a lack of time in 2007, and still found to be reluctant to discuss end-of-life care without a prognosis of 4-6 months in 2010. I will proceed to discuss evidence from studies which show the persistence of these problems.

In 1998, Nicholas Christakis and Theodore Iwashyna surveyed 1311 physicians about their end-of-life care practices in “Attitude and Self-reported Practice Regarding Prognostication in a National Sample of Internists”. According to the study, 89.9% of physicians surveyed believed that it is best to avoid being too specific when making predictions about health status, 60.4% found it “stressful” to make predictions, and 43.7% waited to be asked by a patient before

\footnote{Ibid.}

\footnote{Ibid.}
offering predictions.\textsuperscript{78} To restate, roughly nine out of ten physician explicitly believed they should avoid specificity in helping patients plan for potential decline, while more than a third would wait to be asked by a patient before making predictions at all. Most (80.2\%) believe patients expect too much certainty, while 50.2\% believe that if they were to make an error, patients might lose confidence.\textsuperscript{79} Generalists were 77\% more likely than specialists to reject specificity,\textsuperscript{80} which is significant given that they are most likely to be associated with nursing homes and senior living facilities where ACP should be practiced. With the exception of gerontologists and palliative care specialists, most physicians “dislike making the sort of precise prognoses that patients and policymakers seem to want.”\textsuperscript{81}

Tulsky et al obtained similar results from their study, also conducted in 1998, entitled “Opening the Black Box: How Do Physicians Communicate About Advance Directives?”\textsuperscript{82} They interviewed 56 physicians and their patients at 5 outpatient primary care practices in Durham, NC and Pittsburgh, PA.\textsuperscript{82} Researchers audiotaped care planning conversations to examine how physicians introduced the topic of advance directives, discussed potential scenarios and treatments, provided health information and helped patients to discuss their values and identify potential surrogate decision makers.\textsuperscript{83} Part of the justification for their research was to identify reasons why so few people have advance directives, and why it is that health care institutions

\textsuperscript{78} Christakis, N.A., Iwashyna, T.J. “Attitude and Self-reported Practice Regarding Prognostication in a National Sample of Internists,” 2391.

\textsuperscript{79} Ibid.

\textsuperscript{80} Ibid.

\textsuperscript{81} Ibid.

\textsuperscript{82} Tulsky, et al. “Opening the Black Box: How Do Physicians Communicate About Advance Directives?,” 2.

\textsuperscript{83} Ibid..
often do not rely on them when providing care. Interestingly, in this study, 95% of the physicians interviewed stated that they felt comfortable discussing advance directives with their patients, but 61% still said that they rarely discuss them when providing outpatient treatment.

Patients participating in the study had to be 65 or older, have a serious medical illness (such as cancer, congestive heart failure, or kidney failure) which would make advance care planning relevant, be deemed by their physician to have decisional capacity, and to not have discussed advance care preferences prior to this occasion.

Researchers found that the median advance directive discussion lasted 5.6 minutes, with physicians speaking 3.9 minutes and patients speaking 1.7 minutes. When introducing the topic, 93% of physicians gave an explanation for why they were bringing up advance directives, but 20% attributed this to a research project rather than trying to honestly justify their value to the patient. More often than not, the conversation ended without any specific follow-up plan: just 43% mentioned the possibility of future conversations, 55% discussed advance directive forms, and 25% asked patients if they had any further questions. Physicians generally did not acknowledge the emotional difficulty of having discussions about end of life. Only 29% acknowledged the emotional difficulty of planning for one’s decline and eventual death, and 39% reassured the patient that their health did not prompt this discussion-- despite the fact that each patient needed to have a serious medical illness, e.g. cancer, kidney failure, etc., in order for

---

84 Ibid.
85 Ibid., 6.
86 Ibid., 3.
87 Ibid., 7.
88 Ibid.
89 Ibid.
their doctors to recommend that they participate in this study.\textsuperscript{90} In other words, more than a third were willing to lie rather than admit that their patient’s health did prompt the discussion, and just under a third even acknowledged that these conversations are emotionally difficult. Thus, 10 years after the Patient Self-Determination Act, physicians were still struggling to confront patients’ concerns about end-of-life care.

Finally, the preferences elicited in doctor-patient advance care planning discussions were not especially helpful for gauging preferences in more common scenarios related to chronic debilitating conditions. Physicians opted to discuss dire scenarios where patients would be permanently unconscious, indefinitely confined to the ICU, about to die or otherwise futile scenarios in the vast majority, 91%, of discussions.\textsuperscript{91} 48% of physicians also opted to discuss reversible conditions where cure was assumed and patients were projected to resume ordinary, premorbid functioning.\textsuperscript{92} Most patients prefer to withdraw treatment in dire scenarios, and are willing to undergo treatment if they can reasonably expect to return to their ordinary lives. But these two scenarios are far less common at end of life than a slow, ambiguous decline. 55% of physicians did discuss preferences regarding treatment scenarios where the result would be unpredictable, but only 29% discussed preferences regarding what is perhaps the most common scenario: where a treatment is unpredictable but carries the risk of resulting in or worsening chronic disability.

These are serious issues for the medical field, to which medical education ought to have responded. Five years later, students and residents were still reporting they were inadequately

\textsuperscript{90} Ibid.

\textsuperscript{91} Ibid., 8.

\textsuperscript{92} Ibid.
trained to assist their patients at end of life. In the 2003 article “The Status of Medical Education in End-of-Life Care: A National Report”, Amy Sullivan et al find that medical students and residents felt unprepared to provide adequate care for dying people, while faculty and teaching physicians felt unprepared to teach end-of-life care.  

This study draws from a sample of 1,455 students, 296 residents, and 287 faculty affiliated with a random sample of 62 accredited U.S. medical schools. As with the studies from 1998, medical students and physicians were confident about their ability to provide good end-of-life care: more than 90% held positive views about “physicians’ responsibility for and ability to help dying patients.” But the findings did not support such confidence, and results revealed that more education and preparation is needed to help physicians conduct ACP. More specifically, Sullivan et al found that:

...[F]ewer than 18% of students and residents received formal end-of-life care education, 39% of students reported being unable to address patients’ fears, and nearly half felt unprepared to manage their feelings about patients’ deaths or help bereaved families. More than 40% of residents felt unprepared to teach end-of-life care. More than 40% of respondents reported that dying patients were not considered good teaching cases, and that meeting psycho-social needs of dying patients was not considered a core competency. Forty-nine percent of students has told patients about the existence of a life-threatening illness, but only half received feedback from residents or attending [physicians]; nearly all residents had talked with patients about wishes for end-of-life care, and 33% received no feedback.

So, fewer than one in five medical students and residents received any formal training in death and dying, while almost half of the sample group had to discuss a life-threatening illness with a patient in practice. Of this latter group, only half got feedback from a supervising physician, while about a third got no feedback at all. This is perhaps unsurprising, given that “more than 40% of respondents reported that dying patients were not considered good teaching cases, and

---


94 Ibid.

95 Ibid.

96 Ibid.
that meeting psycho-social needs of dying patients was not considered a core competency.” As for what might account for this, researchers indicate there is skepticism of ADs within the medical establishment, and a common sentiment among providers that living wills have failed in particular.

Granted, these studies were all conducted well before Castillo’s groundbreaking analysis of the divide between clinical practice and legal procedure in 2011, but these are the attitudes which contributed to such a divide. More recent analysis shows that medical education has made some gains, but has not yet translated them into outcomes at the level of patient care. A 2016 study, “Educational interventions to train healthcare professionals in end-of-life communication: a systematic review and meta-analysis” by Han-Oh Chung et al, found some benefits to additional end-of-life care skill interventions in medical education. Namely, self-efficacy, i.e. participant’s confidence in being able to complete a task, improved after educational intervention, as did knowledge according to test scores on end-of-life communication and decision making. There were also improvements on communication scores using a standardized checklist during a hypothetical patient encounter. However, these are simply the results as compared to medical education without these interventions, and there is not necessarily evidence to indicate these improvements in educational outcome would transfer over to clinical practice, nor is there evidence of these interventions becoming more of a standard for medical

97 Ibid.
100 Ibid., 2.
101 Ibid.
education in general. In fact, I suspect medicine is reluctant to allow studies of end-of-life care practices as comprehensive as those of the late nineties simply because there have not been widespread changes to medical education, and it might thus be assumed that results in practice have not improved much either.

Additional factors have not changed since the late nineties: physicians are still faced with insufficient time to conduct good quality conversations about end-of-life care with their patients, and most remain hesitant to discuss preferences until the prognosis is bad. A 2007 study notes that physicians continue to cite lack of time as the main reason they do not engage in end-of-life care planning conversations with patients, while patients cite deferring to family or planning to do it later as the reasons they do not seek to complete ADs.\textsuperscript{102} This study also points to a lack of continuity in care as among the primary reasons patients are hesitant to broach the subject of end-of-life care with their clinicians.\textsuperscript{103} A 2010 study on end-of-life care communication surveying 4074 respondents found that 65% would only discuss prognosis if the patient had 4-6 months to live, while just 44% would discuss DNR status and only 26% would discuss hospice care or preferred site of death.\textsuperscript{104} It is surprising that ten years later and with evidence supporting the value of end-of-life care conversations, physicians are still very reluctant to engage in them. Yet, when few of the structural and economic realities of the health care system have changed since the nineties and many have worsened, it might be expected that end-of-life care has not improved much either.


\textsuperscript{103} Ibid.

Studies by Silveira et al among others suggest that physicians will, for the most part, comply with patient preferences as stated in an AD. This is the case particularly when these indicate comfort measures only. But there is also evidence that physicians are motivated by fear of legal liability when treating dying patients. In a 2012 study, Burkle et al found that most doctors believe their liability is greater if they mistakenly fail to provide resuscitation efforts than if they resuscitate someone against their wishes. The means that most prefer to err on the side of aggressively treating a patient when their wishes are unclear or when the patient does not have decisional capacity. This presents an ethical issue for the majority of patients, as most dying and chronically ill persons do indicate a preference for treatment limitations or comfort measures only. In fact, Burkle and colleagues found that fewer than half of physicians surveyed would honor the AD of a patient in ventricular fibrillation whose stated desire was “to pass away in peace”. Granted, honoring an advance directive is not necessarily equivalent to honoring the preferences of a decisional dying patient or their health care agent, but the fact that legal liability is a such significant motivating force shows that there is still medical resistance to adhering to ADs.

**Conclusion**

“[T]he single biggest problem in communication is the illusion that it has taken place” is a quotation widely misattributed to the playwright George Bernard Shaw which also captures

---


106 Ibid.


108 Ibid.

109 [https://quoteinvestigator.com/2014/08/31/illusion/](https://quoteinvestigator.com/2014/08/31/illusion/)
the reason why efforts at ACP have been so unsuccessful. Legal language and requirements are unclear and vary by state; even when patients have ADs, they do not always reach the health care practitioners who should abide by them. People are hesitant to think about their own decline, and not especially willing to try to communicate with loved ones about how they want their lives to end. Doctors are not trained to communicate about decline, and they avoid doing so until it is often too late. Meanwhile, caring for dying people is not even considered a “core competency” of medical education. I argued in the previous section that the health care system has a responsibility to help people achieve appropriate death, and it should be clear from this section that it has failed in this responsibility. Overall, the reasons for this failure are relational: they have to do with the ways we communicate with one another in the service of our agency, and how we then go on to communicate with health care providers. The next section will offer a theory which expresses how interactions determine personhood, and argue for an alternative approach to advance care planning on this basis.
CHAPTER FIVE

WHY PRACTICE ACP?

A CASE FOR HOLDING

Introduction

This chapter provides an answer to the question of why we ought to practice advance care planning or ACP despite the history of its inefficacy. Hilde Lindemann argues that the practice of personhood is essentially interpersonal in nature.1 Her argument is a premise for the morally valuable form of holding I take to operate in the advance care planning process. Each person is “held” in their identity by others, groups, and ultimately by their own perspective on significant interactions. When someone is too sick to be able to hold on to their identity on their own, those who care for them should step in to support more significant aspects of their personhood in decline.

The first section of this chapter focuses on these significant aspects of Lindemann’s definition of holding. Among Lindemann’s examples of this involves a retired professor, Edmund, and his friend and former colleague, Charlie. Section two retells this anecdote, which concludes with Edmund dying a tragic death in the hospital while Charlie is unable to save him from being subjected to treatments which were most likely against his wishes. If Edmund had undergone a more robust process of ACP, Charlie and his other loved ones could have better anticipated his death. The network of people and trusted care providers who might have held

---

Edmund in his dying process could have been better identified and mobilized, and his agency did not have to collapse in the way that it did.

Lindemann points out various ways the health care system is set against planning for decline, namely the norm of overtreatment in response to what Daniel Callahan calls the threat of “wild death”, along with role-related bias among physicians in favor of treatment. In section three I characterize this as the health care system’s tendency to hold on to life. This is not necessarily objectionable in cases where cure is likely, but it can present a serious moral harm in cases where shifting to care would be preferable. Life might not hold as much significance if a person’s character and values are overridden by unpredictable suffering, or if friends and family cannot defend their loved one’s preferences.

The health care system needs to be redesigned in ways that not only avoid a crisis response as much as possible, but in ways that help people who are potentially dying achieve appropriate or “tame” deaths. It is unreasonable to expect that patients will independently have the expertise needed to manage this task on their own. Thus, we ought to train and compensate care planners who can practice the kind of holding needed to facilitate appropriate death. I call the kind of holding involved in ACP “boundaried agentic holding”: which is different from the kind of identity work surrogate decision makers engage in, and the holding on to life typical of the health care system. In section four of this chapter, I introduce the Respecting Choices model of ACP as an example of boundaried agentic holding, and conclude by demonstrating that Edmund could have achieved a more appropriate death if he had received the support and guidance of a care planner.
Lindemann’s Concept of Holding

This section sets the groundwork for my claim that advance care planning is a process of holding, where care planners and surrogate decision makers attempt to hold someone’s personhood throughout the dying process. I will first clarify what moral philosopher Hilde Lindemann means by holding in the text *Holding and Letting Go: The Social Practice of Personal Identities*. Lindemann argues for the essentially interpersonal nature of personhood and identity.² Holding someone in personhood is an interactive, fundamentally social process that draws from potentially relevant narratives and applies them in ways that constitute identity.³ For Lindemann, designating a surrogate decision maker expresses the belief that they will be able to hold you in your identity well⁴, even perhaps when you are unable to hold on to yourself. I conclude this section by applying Lindemann’s notion of holding to the advance care planning process. Specifically, I take the process of care planning to unfold successfully when care planners, patients’ friends and families, along with the health care practitioners they choose to involve “hold” the patient in their values throughout the dying process.

Along with many contemporary philosophers, Hilde Lindemann accepts that being human is a fundamentally interpersonal condition.⁵ Initiating human beings into personhood is not just a social practice: it is also a moral one according to Lindemann. Human beings must be “inducted” into personhood through the same social interactions by which we acquire linguistic,

---

³ Ibid., x.
⁴ Ibid., 177.
⁵ Lindemann argues this on pg. 202 of *Holding and Letting Go*. Other philosophers who accept this position would include communitarian authors such as Bruce Jennings and Daniel Callahan as well as relational autonomy theorists such as Diana Tietjens Meyers, Carolyn MacLeod, and Susan Sherwin. Kathryn Abrams’ theory of agency also starts from this basic tenet.
rational, and moral agency. To be “held” in personhood is an interactive process involving other people who recognize us as persons and respond accordingly. Personhood is the ground on which personal identity rests, she argues. Personhood has four elements:

…(1) A human being has sufficient mental activity to constitute a personality, (2) aspects of their personality are expressed bodily, (3) other persons recognize it as the expression of a personality, and (4) they respond to what they see. Recognition and response are often a matter of understanding who someone is and treating them accordingly. Whether these understandings are self-conceptions or others’ sense of who we are, they consist of a web of stories depicting our most important acts, experiences, characteristics, roles, relationships, and commitments. This narrative tissue constitutes our personal identities, which play a crucial role in the practice of personhood.

Personhood is a complex and dynamic process, involving specific others and social groups. Initially, the person in question should have sufficient mental activity to express a personality. Lindemann begins the book with the story of her sister, whose significant cognitive impairment complicated but did not cut off the expression of her personality. Although she died at only seven years old, Carla was able to give bodily expression to her feelings, thoughts, desires, and intentions in ways that her family could recognize and respond to. Having a personality and being able to express it bodily are the most basic elements of personhood, however. It is more complicated to be recognized by others, and for those others to understand and respond in ways that reflect an individual’s personhood. This is better understood as work which goes into the establishment of personal identity, or “identity-work” according to Lindemann.

---

6 Ibid.
7 Ibid., 203.
8 Ibid., 57.
9 Ibid., ix.
10 Ibid., 15.
11 Ibid., 23.
Like personhood, personal identity is a social practice and not a static construct.\textsuperscript{12} In fact, personal identity may be the most fundamental social practice, given that it is what “...allow[s] us to live well in the sphere of moral consideration reserved for persons...”.\textsuperscript{13} In order to establish a personal identity, people need to discern the rules by which other people can apprehend the features of identity we aim to project. Because personal identity has to be acted out for others, it often relies on what Lindemann calls “common stock”, or shared, sometimes stereotypical representations of personal identities.\textsuperscript{14} Personal identities are ways of depicting the self: we act or refuse to act according to certain standards, and in doing so we indicate how we wish or expect to be treated.\textsuperscript{15}

Processes of holding or letting go can be applied to someone’s life, personhood, or personal identity.\textsuperscript{16} In most cases, it is best to hold someone in their life; for Lindemann, if it is morally defensible to let go of someone who could be held in their life, this is a tragic circumstance.\textsuperscript{17} Personhood, however, gives us a sense of self and cannot be accomplished without the involvement of the others who hold and maintain us.\textsuperscript{18} To reiterate, ordinary personhood is the practice of physically expressing one’s personality to others who recognize the expression for what it is and respond accordingly.\textsuperscript{19} These interactions invoke narratives—some

\textsuperscript{12} Ibid., 202.
\textsuperscript{13} Ibid.
\textsuperscript{14} Ibid.
\textsuperscript{15} Ibid.
\textsuperscript{16} Ibid., 22.
\textsuperscript{17} Ibid., 28.
\textsuperscript{18} Ibid., 23.
\textsuperscript{19} Ibid., 97.
accurate and others distorted—that lead to the construction of identity. Identities, once again, typically operate at a higher level of abstraction than life and personhood. They can extend beyond personhood and life,\(^{20}\) which means identity can be held or maintained after a person dies.

Holding someone in personhood is not necessarily as complicated as holding them in their identity, and can sometimes be as simple as the acknowledgement strangers give one another in public places.\(^{21}\) Holding someone in a particular identity, however, involves a richer interactive history. For example, if you were to see a friend crying, she is “..performing a particular persona in distress”, and you would respond by drawing from your own sense of who you are in relation to her.\(^{22}\) You might have grounds for responding in ways that indicate she is being a drama queen, or you might hold her in a more sympathetic way and try to understand what is causing her distress.\(^{23}\) Either way, your response is legitimate or not according to the moral norms that arise impersonally from your respective identities.\(^{24}\) More specifically, standards of being a good friend, or an honest person determine the moral worth of your response, while we might also make moral judgments about her character in response to the cause of her distress.

Significantly, Lindemann specifies that maintaining someone’s identity requires a foundation of trust.\(^{25}\) To review, holding someone in personhood is not as demanding as what

\(^{20}\) Ibid., 29.

\(^{21}\) Ibid., 203.

\(^{22}\) Ibid., 204.

\(^{23}\) Ibid.

\(^{24}\) Ibid.

\(^{25}\) Ibid., 144.
Lindemann calls “identity work”, which works through each of the four criteria required for personhood to contribute to the formation and maintenance of someone’s character over time. Trust is key for identity work. If we cannot trust the others around us to recognize and respond to the way we understand ourselves, the interpersonal context that constitutes identity breaks down.26

Like Lindemann’s sister Carla, a person does not have to be able to contribute a first-person perspective or forward their own narrative to have a personal identity.27 Yet, full participation in personhood requires that a person come to an understanding of who they are, act on the basis of this understanding, respond to the stories other people deploy about them, and contribute their own interpretation of other people’s identities.28 In situations where full participation in personhood is impossible, it becomes the responsibility of others to empathically fill in the gaps someone might experience and support potential expressions of their personal identity. Thus, the kind of “holding” we undertake with respect to others’ personal identities can be more or less demanding of us.29

When someone’s ability to understand themselves and contribute a first-person to their experiences declines, it becomes the task of those who care for them to support their personhood and strive to maintain their identity.30 For example, if someone suffering from dementia becomes

26 Ibid.
27 Ibid.
28 Ibid.
29 Although I would not want to assume that holding someone whose cognitive functioning might be in decline or holding someone with a developmental disability would necessarily be more demanding than holding an otherwise neurotypical person. If the latter person was wrong or mistaken about a fundamental aspect of experience, refused to be persuaded otherwise, and reacted violently to your efforts to enlighten them, they would probably be harder to support than someone navigating cognitive limitations.
30 Ibid.
easily agitated, confused, and seems to repudiate the values they held while they were relatively well, holding this person well would involve consideration of who they were over time. The person who wants to hold them should respond to a multitude of the narratives and interactions that formed the relationship, and it would be wrong to fully discard the former self in favor of the more recent self, or vice-versa.

Nevertheless, holding someone well involves recognizing and giving priority to the version of the self which is more associated with better health and fuller agency. Lindemann draws from neurosurgeon Grant Gillett to interpret the shaping of the human self as similar to the weaving of a tapestry: claiming that the demented self is the “real” self would be like claiming that a damaged, moth-eaten tapestry is equally representative of their personhood in decline.31 If the “real” self exists, it would be a composite of multiple intersecting narratives with priority given to those that unfolded while the person in question was in more tolerable health and had greater agency.

Holding someone in personhood can be performed by friends and family members, but it is especially important for those who take on the responsibility of becoming surrogate decision makers. Surrogate decision makers “…[hold] on to the patient as the person they have known and cared about, making decisions that reflect that understanding of who the patient is.”32 With respect to surrogate decision making, holding has probably been going on for years and can be of great moral importance.33 This is not to say that all holding goes on well: it can be done badly if the one doing the holding has a mistaken view of who the person is.34 However, surrogate

31 Ibid., 133.
32 Ibid., 176.
33 Ibid., 177.
34 Ibid.
decision makers have reason to believe the kind of holding they do is wanted and welcome; designating a surrogate in the first place expresses someone’s belief that this is a person who can hold them well.\textsuperscript{35}

Although it would be prudent for a surrogate decision maker to ensure that health care professionals are neither overzealous nor neglectful in their care, their primary responsibility is making decisions on behalf of their loved one.\textsuperscript{36} They are, once again, most likely to have been appointed as a surrogate because they have been successfully holding the personhood and maintaining the identity of their loved one. They are also most likely trusted over care providers and institutions.

It is clear that someone bears responsibility for ensuring that care provision happens in ways that are not overzealous, neglectful, or contradictory to patients’ more deeply held values, however. Patients across the spectrum of wellbeing have an interest in sharing preferences and setting boundaries in accordance with their sense of personal identity. As tragic as it is to let go of someone’s personhood while there is still a chance for life, it is equally tragic to maintain them in a form of personhood that not only goes against their values, but may be painful, humiliating and costly. If the health care system is to be trusted by those whose wellbeing it purports to serve, it ought to support patients in creating the alliances and fostering the kind of agency that would prevent tragic and traumatic deaths.

Although Lindemann associates surrogate decision making with holding someone in personhood, I would adapt this claim somewhat to argue that collaborating with a loved one and holding them through difficult health care decisions is a form of identity work. Concurrently,

\footnotesize{\textsuperscript{35} Ibid.}

\footnotesize{\textsuperscript{36} Ibid., 176.}
health care institutions have an obligation to respect and support the kind of holding people deserve in the dying process. As I will explore in section 3, health care institutions tend to hold on to life for more and less legitimate reasons. However, a better approach would involve designating a class of caregivers to engage with patients of all health statuses, who could identify friends and relatives who have the kind of history to support someone’s identity in decline. The motivating assumption for such a process is that a trustworthy health care system should not default to a crisis response, or lapse into overtreatment or neglect. Instead, it could employ care planners to achieve three key goals of ACP. First, patients should have guidance exploring and articulating their values. Second, it should be among the goals of ACP that they formalize their alliances with the people who maintain their identity in deeper ways. And finally, the ACP process should identify clinicians who will work with the patient to promote wellbeing or manage decline in ways that are respectful of patients’ sense of self.

Advanced care planning (ACP) could thus be understood as a kind of holding. ACP does not go quite as far as identity work, but it recognizes the reality that every person faces death, and it responds to the moral demand that everyone should be entitled to a decline which avoids unnecessary suffering and trauma. To review Lindemann’s four criteria of personhood, the efforts of care planners on behalf of their clients would center around points three and four: that other persons recognize the expression of a personality, and that they respond to what they see.37 Yet, there is also a sense in which conventional health care provision recognizes and responds to people’s more basic health needs, holding them in perhaps a more immediate response to questions of survival. I will turn to an example of Lindemann’s in the subsequent section to clarify the distinction I read into her analysis of holding.

37 Ibid., ix.
A Dilemma in End of Life Care: Edmund and Charlie

This section will focus on a dilemma regarding why we ought to practice advance care planning (ACP). To uncover some of the reasons for the importance of ACP, I will retell a narrative crafted by Hilde Lindemann in the book *Holding and Letting Go: The Social Practice of Personal Identities*. The dilemma involves an eighty-five year old man and his friend who had promised to help him die at home. Now that emergencies have become increasingly common thanks to the COVID-19 pandemic, the default option for many older adults is to go to the emergency department. Once there, it can be difficult to get the support required to make good treatment decisions, aside from potential isolation, the trauma of institutionalization itself, and the threat of neglect. Lindemann argues that the friend and surrogate decision-maker, Charlie, is practicing one kind of “holding”, while his doctor performs another kind of holding. I will first introduce the narrative, and then address the different forms of holding at work.

Edmund is an eighty-five year old professor emeritus of medieval European history and appreciator of classical music who lives with his beloved cat, Tosca. His living room is mostly undecorated so that Tosca can have room to lounge and play. Although Tosca has two scratching posts, it is clear she prefers to sharpen her claws on Edmund’s furniture. His friend Charlie is also a specialist in medieval European history, and visits Edmund about once a week to discuss mutual research interests and share stories about their mutual former department. One night, Edmund calls Charlie deeply frightened as he is experiencing shortness of breath and pressure in his chest. Charlie breaks the speed limit getting him to the hospital, where the cardiologist tells Edmund he will need a heart catheterization to see which arteries or vessels were occluded. Charlie does his best to reassure Edmund before the procedure:

---

38 Lindemann describes this dilemma in pgs. 160-65 of *Holding and Letting Go*. I will summarize it pgs. 8-10 herein.
“I’ll be right here,” he promised. “You’re going to be okay.”

“Who’ll look after Tosca?”

“It’s all taken care of. I phoned your neighbor.”

“If I’m dying, don’t let me die here. Let me die at home, with Tosca.”

“You’re not dying.”

Do they know you’re my decision maker if anything goes wrong?” he asked.

“Yeah, it’s in your chart. Nothing’s going to go wrong, though. They’re going to fix you up.”

“I want to die at home.”

“I know.”

During the procedure, Edmund suffers a second, massive heart attack and requires emergency surgery. He survives, but when Charlie goes to visit him in intensive care the next day he is ashen-faced, unresponsive, and has many tubes running through his body. Charlie continues to visit Edmund, but sees little improvement.

Despite Edmund’s apparent deterioration, his cardiologist Dr. Stoddard remains consistently upbeat. Insufficient blood is reaching Edmund’s kidneys and they begin to fail; Edmund is too sick to eat, so the care team places a nasogastric tube. By the third week, Edmund develops pneumonia and is put on a ventilator for 72 hours. Charlie is concerned about all of this, and tells Dr. Stoddard that they had signed a Declaration of a Desire for a Natural Death five years ago. This document stipulated that “if my condition is determined to be terminal and incurable, my physician may withhold or discontinue extraordinary means, artificial nutrition or hydration, or both.”39 After Edmund fails a lung function test 72 hours later, Charlie makes an appointment with Dr. Stoddard to advocate for his friend’s wish to die in peace. Dr. Stoddard is initially surprised, and insists that Edmund isn’t dying, his pneumonia is clearing up, and his kidney function has been much better. In fact, the doctor wants to place a PEG tube in his abdomen to try to get his weight up, since the nasogastric tube is bothersome, and wants to perform a tracheotomy to help him breathe. Charlie is appalled and protests: “He’s been very

clear from the beginning he doesn’t want to end up like this. Please don’t keep doing things to him. Please—it’s got to stop.”

Dr. Stoddard is unmoved, and attempts to persuade Charlie of the value of going on with a more aggressive treatment plan. He replies:

“I sympathize with what you’re going through, but you have to understand that patients don’t always mean what they say. I’ve seen it so often, people telling me they don’t want to live if it means being on oxygen the rest of their lives, or being bed-bound, or having to go into a nursing home. But when they find themselves in that situation, they discover it’s not as bad as they thought it would be.” He gave him a wry little smile. “It’s certainly better than being dead.”

In Dr. Stoddard’s view, Edmund’s recent setbacks are reversible. Charlie pushes back: even if Dr. Stoddard has grounds to make this generalization, Charlie is certain his friend would not have wanted to end up in this situation, and would want to be allowed to go home even if it means risking death. Dr. Stoddard adamantly maintains that it is not yet time to give up, and that Edmund would likely have changed his mind given the circumstances. The doctor then proposes that they take Edmund off sedation so that they can ask him if he wants to continue treatment.

Lindemann notes that many people’s intuitions would likely line up with Dr. Stoddard’s proposition at the end: that we ought to simply get the patient into a state where he can give or withhold his consent. Charlie might be well intentioned on behalf of his friend, but Lindemann suggests he may be exceeding his authority when he hesitates to give Edmund the opportunity to change his mind.

In the end, Lindemann does not explicitly prescribe or defend a specific course of action with respect to the end of Edmund’s life. In fact, the care team did awaken Edmund: he was too

---

40 Ibid., 163.
41 Ibid., 165.
42 Ibid.
ill to communicate his wishes, and died a few hours later.\textsuperscript{43} She does say that Charlie is probably right to want Edmund to be allowed to die without further treatment.\textsuperscript{44} This is in part because the kind of holding Charlie is practicing is that of a friend who held him in a deeper level of personhood that the kind of “Patient” personhood by which his care team understands him.\textsuperscript{45}

This is not to say that holding on to life is necessarily wrong—as noted earlier, many instances where we have to let go of our efforts to hold someone in their life are tragic.\textsuperscript{46}

I have alluded to the problem that the kind of generalized holding on to life practiced by the health care system can be at odds with more nuanced forms of identity work carried out by friends and family members. Section three will elaborate on Daniel Callahan’s claim that holding on to life in the face of the threat of “wild death” makes an appropriate death even more elusive. Appropriate or “tame” deaths make space for the dying person and their loved ones to anticipate death in meaningful ways. The morally significant interactions which take place therein would fall under Lindemann’s category of identity work. While identity work is distinct from holding on to life in the health care system, it does not have to be opposed to it. Section three concludes by distinguishing three forms of holding at work in end of life care: holding on to life, identity work, and what I will call “boundaried agentic holding”. Boundaried agentic holding is the sort which should be at work in the ACP process, and which ought to support the agency of people who may be facing chronic illness and death.

\textsuperscript{43} Ibid., 175.
\textsuperscript{44} Ibid., 176.
\textsuperscript{45} Ibid., 176.
\textsuperscript{46} Ibid., 28.
Holding on to Life in the Health Care System

In crisis scenarios such as Edmund’s, the default response is often to rush to the emergency department, which can subject people who may be in the dying process to more aggressive forms of treatment they may not want. Once in the hospital, patients must navigate a system that tends to prioritize intervention, where refusing treatment can be a sign they are not competent to make their own medical decisions. The kind of holding carried out by the care team prioritizes persons as patients: each is a case to be treated according to the precedent set by medically shared master narratives. This is not necessarily bad, and is certainly beneficial for otherwise healthy people with a good chance of returning to relative health and independence. But with respect to chronic illness and end of life care, holding on to life in the manner characteristic of ordinary medical practice can be at odds with the deeper identity work carried out by friends and loved ones, especially when the illness substantially threatens someone’s sense of self.

This section introduces the concepts of “wild” vs. “tame” deaths—a distinction Hilde Lindemann adopts from Daniel Callahan. In trying to stave off wild death, the health care system can end up subjecting people to unpredictable forms of suffering. Appropriate deaths, on the other hand, can be anticipated in ways that allow a network of caring persons to be established or reconfigured. In the end, I will claim that there are three kinds of holding which should be at work in the health care system. First, surrogate decision makers and loved ones should support the character and values of chronically ill and potentially dying through identity work. The health care system is not necessarily wrong to hold on to life, but it could do a better job of recognizing that this is not appropriate for many people, and help them devise an alternative approach if a health crisis does occur. It could accomplish this through “boundaried agentic
holding”. This kind of holding could supplement the current approach by focusing on the values and preferences people have for the dying process, and working to ensure that these are known and respected by both the friends and relatives of the client as well as their care team.

In *The Troubled Dream of Life*, Daniel Callahan draws from the writer Phillipe Ariès to distinguish between a “wild” versus a “tame” death. While I was critical of Callahan’s communitarian position regarding end of life care in Chapter 2, I argue here that ACP should be among the practices which help avoid the threat of wild death. A wild death is more common in a society where health care provision is driven by continuous advances in biomedical technology. Technology conditions the possibility of wild death, which is marked by fear and uncertainty, by the presence of medical powers we are not fully able to control, and by a course of decline that may leave us isolated and degraded. On the other hand, a tame death is “tolerable and familiar, affirmative of the bonds of community and social solidarity, expected with certainty and accepted without crippling fear.” A death which can be anticipated and accepted by the dying person and those who care for them is certainly preferable to a wild, unpredictable death. I would add that bonds of community and social solidarity cannot be taken for granted: it is important to form these bonds through counterstories and shared support for the agency of chronically ill and dying people.

Drawing from Callahan, Hilde Lindemann argues that the medical practice surrounding the culture of wild death is governed by a powerful norm: that it is worse to err on the side of

---


50 Ibid.
letting a patient die prematurely than it is to err by overtreating the patient.\textsuperscript{51} As I noted in the previous chapter, “Historical Failures of ACP”, there is empirical evidence for this as well. Burkle et al’s 2012 study found that most doctors believe their liability is greater if they fail to provide resuscitation efforts than if they resuscitate someone against their wishes.\textsuperscript{52} In practice, many do prefer to err on the side of treating a patient when their wishes are unclear or when the patient does not have decisional capacity. This presents an ethical issue for the majority of patients, as most dying and chronically ill persons indicate a preference for treatment limitations or comfort measures only.\textsuperscript{53} Additionally, the trauma of being institutionalized and isolated—a far more likely scenario thanks to the COVID-19 pandemic—means that more patients stand to suffer in ways that prevent them from making good decisions about their care preferences or sharing them with health care providers. The health care system ought to be reconfigured to cope with this problem: it could train practitioners to engage with patients and help them think through and clarify their preferences before a crisis triggers emergency protocol. It needs to acknowledge it has some responsibility to balance a patient’s survival with their relationships and agency, and adapt accordingly.

Another important characteristic of the medical field Lindemann raises is that physicians tend to have a role-related bias in favor of treatment.\textsuperscript{54} This is a claim initially made by Robert Veatch in the article “Who Should Manage Care? The Case for Patients”. Most professionals


\textsuperscript{52} Burkle, et al. “Physician perspectives and compliance with patient advance directives: The role external factors play on physician decision making.” 1.


\textsuperscript{54} Lindemann, Hilde. \textit{Holding and Letting Go: The Social Practice of Personal Identities}, 167.
favor the use of society’s resources for the practice of their profession.\footnote{Ibid.} Lindemann points out that if Veatch is right about this bias, then the burden is on patients to show that refusing further life-sustaining treatment is reasonable.\footnote{Ibid.} To further complicate matters, refusing treatment in and of itself can be a sign that a patient is not competent to make decisions for themselves.\footnote{Ibid., 168.} Thus, it is more often the case that the health care system will proceed by treating patients as fully as possible, especially if they do not have advance directives or surrogate decision makers to impose and defend limitations. This dynamic has a tendency to pit physicians against patients’ family and friends, as I explored in Chapter four. Physicians should be included in ACP where appropriate, but facilitating discussions of care preferences is not necessarily a task for which they are well trained or enthusiastic to undertake. An approach to care planning that started earlier and involved care workers specifically trained to facilitate discussion could happen before people are too sick to consider who they want involved in their care and what kinds of treatments they can tolerate.

As I argued in section two of Chapter one, “COVID-19 in the U.S.: An Exacerbation of Existing Injustice and the Increased Elusiveness of Appropriate Death”, the pandemic has robbed hundreds of thousands of people of an appropriate death. To review, Avery Weisman and Thomas Hackett’s concept of an appropriate death has four key characteristics: the dying person understands they are dying, they have been able to accept their impending death to some degree, they feel the death is timely, and the way in which they are dying coincides with their values and
the values of their chosen community. The aim of the hospice movement is to promote appropriate death, Dr. Weisman notes.

The concept of an appropriate death is related to the idea of a tame death in that they share features of being able to be anticipated by the dying person and their loved ones. This period of anticipation allows for the possibility of those who care for the dying person to hold their loved one in the dying process, and can be of profound moral significance. Granted, it may also provide opportunities for members of a caring network to come into conflict and dredge up old wounds. Yet, these conflicts can also be opportunities to heal and reforge alliances. In cases of persistent abuse or significant trauma, estrangement is not necessarily an objectionable failure of filial piety or family solidarity. For some family members, it can be a valuable opportunity to move forward from past abuse and set new boundaries. Thus, despite the likelihood of conflict around a loved one’s dying process, the possibility of anticipation gives friends and relatives space to reflect on their relational history and their roles in one another’s lives.

Appropriate and tame deaths are characterized by space for anticipation by a caring network in general, and space for the anticipation of the end of someone’s suffering in particular. Whether suffering occurs over an extended period of time or consists in a series of punctuated incidents, it tends to threaten a person’s sense of self: destabilizing agency and self-worth. Drawing from Eric Cassell’s expansion of the concept of suffering to include aspects of personhood such as one’s lived past, culture and society, unconscious mind, as well as the

---


59 Ibid.
Lindemann argues that when we suffer in this sense of the word is also when we most need the help of specific others to hold us in our identities.

I return here to the example of Edmund’s dying process: it unfolds counter to his stated wishes, relies on technologies he likely would have found violating, and causes significant distress to his friend, Charlie. In fact, Charlie is forced to cope with the same kind of moral distress as Lazaroff’s son in Chapter three, only his friend Edmund would likely have rejected the treatments imposed on him. Lindemann does not necessarily claim that Edmund is being threatened with the possibility of a wild death, and certainly Dr. Stoddard does not believe he will be subjected to one. However, these are the kinds of deaths that the advance care planning process aims to prevent. Aligned with the hospice movement, advance care planning asks each person to reflect on what they would want in the dying process. More specifically, care planners could be employed to help patients explore and articulate their values, formalize their alliances with the people who maintain their identity in deeper ways, and identify clinicians who will work with the patient to promote wellbeing or manage decline in ways that are respectful of their sense of self.

The kind of identity work that Charlie can perform as Edmund’s friend recognizes and affirms important aspects of his character, while Dr. Stoddard is holding to a version of Edmund that hinges more on his basic survival and medical prognosis. Charlie is holding on to “Tosca-Edmund” “…who exercised his autonomy by drawing up an advance directive.” Dr. Stoddard, on the other hand, is holding a version of “Patient-Edmund”: the stories which constitute his

60 Cassell, Eric. The Nature of Suffering and the Goals of Medicine, 42.


62 Ibid., 171.
understanding of Edmund are more likely to be drawn from medically shared master narratives that doctors use to depict patients as a group. Both forms of holding are morally valuable. It is to our benefit that doctors can draw from narratives about groups of patients to make predictions about their patients. But life might not hold as much significance if a person’s character and values are overridden by unpredictable suffering, or if friends and family cannot defend their loved one’s preferences. Doctors alone ought not to be charged with discerning when the shift from holding on to life in general versus holding on to a person’s character and values occurs. They are not performing this deeper identity work in their ordinary role, although their expertise is unquestionably valuable when patients and their loved ones are trying to gauge and manage changing symptoms along the dying process.

In my view, there are at least three kinds of holding at work in how to care for people who might be facing death: holding on to life with medical care, supportively holding a friend or loved one through identity work, and a form I will call “boundaried agentic holding”, which is geared toward helping each person manage chronic illness and decline. The health care system holds to a version of each patient as a case to be understood as one among many, comparing symptoms and the success rates of various treatments in an attempt to cure them. In general, it holds to each person’s life in ways which are oriented toward their basic needs and survival. This becomes more complicated when cure is impossible but good care could still provide a tolerable quality of life. However, it is still within the purview of responsibility of the health care system to recognize this reality and admit that it is not only charged with holding on to life. It must also be sensitive to the nuances of the dying process. It could better accomplish this by funding the

63 Ibid.
institutions and personnel who can maintain quality of life for patients in decline and help them plan such that they can avoid wild, intolerable deaths.

Thus, the health care system and society in general ought to recognize the need for care planners who can practice boundaried agentic holding. A care planner practicing this kind of holding understands that they are neither providing direct care for their client, nor are they engaged in the kind of identity work carried out by friends and relatives. This kind of holding respects the interpersonal boundaries of the patient or client, guiding them to designate surrogates they can trust. It also helps them set practical boundaries for treatments they do not want at various stages of decline. Comparable to a social worker, care planners can support patients’ agency: their variable empowerment in socio-political context. In practice, there may be some overlap between these two professions. Social workers help their clients get access to social services and medical care, which may also be the goal of advance care planning. The key difference is that the boundaried agentic holding carried out by care planners focuses on the values and preferences people have for the dying process, and works to ensure that these are known and respected by both the friends and relatives of the client, and their care team. To illustrate what boundaried agentic holding would look like in practice, I will introduce the Respecting Choices model of ACP in the subsequent section. In my view, it is a successful example of how to implement key benefits of ACP. These include such goals as helping patients explore their values for end of life care, identifying supportive alliances with potential surrogates and clinicians, and generating formal advance directives by way of ongoing, informal conversations.
An Alternative Approach: Respecting Choices

Most health care provision operates according to the acute care model: patients are assumed to enter the system for as brief a period as possible, and prescriptions are made such that health and functionality can be restored as quickly as possible. Circumstances where patients have complicated, intersecting medical and mental health diagnoses or other long-term serious illness are not typically seen as the norm for care provision even if they demand a greater proportion of health care resources. In fact, although it is often assumed that last-ditch efforts to save the lives of dying persons constitute the greatest demand on resources, recent studies show that mismanagement of chronic conditions is what strains the system the most. A 2017 study by French et al found that spending in the last three years of life is a much greater share of overall healthcare spending than care provided in the last year of life, which leads these authors to suggest that shifting focus to the treatment of high-risk patients with chronic conditions would be a better use of resources than limiting acute care for people in their final year of life.64

Trying to force chronically ill and disabled patients through an acute-care oriented system is not only impractical, but unethical in that it does not serve the goal of maintaining patients’ quality of life toward the end. Better planning which includes helping patients set limits on the life-extending treatments they want in cases where they may no longer have awareness or decisional capacity would be an important first step toward this goal. An alternative model which supports decision making among patients with chronic conditions is needed to ensure better care and fairer resource allocation. As I stated previously, it is still within the purview of responsibility of the health care system to help people achieve appropriate death. It ought to

---

64 French, Eric B., et al. “End of Life Medical Spending In Last Twelve Months of Life Is Lower Than Previously Reported,” 1215.
invest in a method of advance care planning which practices boundaried agentic holding: helping people navigate interpersonal boundaries about who they want involved in their care, and setting practical boundaries about what kinds of treatments they do or do not want in the end.

One such model is the Respecting Choices program, developed at Gundersen Lutheran Hospital in LaCrosse, WI. Atul Gawande references this program in Being Mortal, and its methods and worthy results are well documented in bioethics literature. This program provided the elderly and disabled residents of La Crosse with support and guidance expressing and documenting their care preferences, which resulted in better care and lower costs. As noted by Gawande and supported by Medicare data, [patients] spent half as many days in the hospital as the national average during their last six months of life, with no sign that doctors or patients were halting their care prematurely. Despite average rates of obesity and smoking, life expectancy in LaCrosse outpaces the national average by a year.”

In the mid-1980s, Gundersen’s clinical ethicist Bernard Hammes, began studying care outcomes in the cases of patients with end stage kidney disease who had suffered devastating strokes. Healthcare providers expected these patients to survive for some time if dialysis was continued, but they did not expect that these patients would ever regain awareness of self, others, or their surroundings once lost. This marked a need to initiate conversations about what kinds of life sustaining treatments would be preferable before patients became incapacitated. By the 1990s, and after a campaign by local medical leaders, it became routine for all patients admitted

---

65 Now Gundersen Health System.
67 Thompson, Jeff. “Putting the Patient and Family at the Center of the Care Model: Why We Did It…The Value of Care Planning to Our Patients and Their Families.” Having Your Own Say, 6.
68 Ibid., 7.
to a hospital, nursing home or assisted living facility to meet with someone experienced in these conversations to fill out a form which asked four principal questions:

1.) Do you want to be resuscitated if your heart stops?
2.) Do you want aggressive treatments such as intubation and mechanical ventilation?
3.) Do you want antibiotics?
4.) Do you want tube or intravenous feeding if you can’t eat on your own?  

These are essentially the same questions asked on the Physician’s Orders for Life-Sustaining Treatment or POLST form today. Even though the questionnaire does not cover a wide array of possible complications, having some indication of a patient’s wishes was helpful to the care team. In the words of one critical care specialist at Gundersen, “[t]hese things are not laid out in stone…” There are inevitable complexities in each case, “[b]ut instead of having the discussion when they get to the ICU, we find many times it has already taken place.”

Since every admitted patient is asked to meet with a care planner and record their preferences, it is often the case that preferences will change according to age and severity of the diagnosis: someone admitted to deliver a child may have very different answers from someone admitted for complications of Alzheimer’s disease. However, Gawande points out that it was the discussion, not the documentation that mattered most: “Discussion had brought LaCrosse’s end-of-life costs down to half the national average. It was that simple—and that complicated.”

In the original initiative, many different kinds of people in LaCrosse opted to become trained in care planning. Volunteers, retirees, and parish nurses all chose to sit with their friends,

---


70 Ibid., 180.

71 Ibid.

72 Ibid.
families and community members to discuss how they wanted their lives to be lived. Dr. Jeff Thompson’s reflection on the history of the project mentions that rather than feeling pressured by government or healthcare authorities to engage in care planning, most of the planners and their interlocutors felt that this was an important community-wide effort. According to Bernard Hammes, the LaCrosse model “starts from the assumption that it is necessary to redesign the health system so that, as a matter of routine, it is focused on the person and knowing the values and goals of each person.” Hammes claims that this kind of “patient-centered” care is “not inherently about individual autonomy or legal rights…”, the goal is to understand each person’s views, values, history and relationships, and to rely on these when making decisions about the benefits and burdens of medical treatments. While documenting preferences on an advance directive and designating a surrogate decision maker are important, Hammes echoes the sentiment that they are secondary in importance to initiating conversations with patients and their loved ones about care preferences.

There are three stages to care planning according to the LaCrosse model. First, when people are healthy, conversations are geared primarily toward basic planning and designating a power of attorney for healthcare (POAHC). The patient and the POAHC clarify hypothetical possibilities and then settle on specific instructions for what to do in cases where the person loses

---

73 Thompson, Jeff. “Putting the Patient and Family at the Center of the Care Model: Why We Did It…The Value of Care Planning to Our Patients and Their Families.” Having Your Own Say, 8.

74 Ibid.

75 Hammes, Bernard J. “Creating Person-Centered Care When It Matters Most: Lessons Learned at Gundersen Health System.” Having Your Own Say, 13.

76 Ibid.

77 Ibid.

78 Ibid., 14.
decisional capacity and the goals of treatment change from prolonging life to providing comfort.\textsuperscript{79} For persons with a progressive, advanced illness, planning becomes disease-specific and anticipates complications which alter the goals of care.\textsuperscript{80} Finally, if it is likely that a person will die of their illness in the subsequent year, conversations proceed in greater detail and refer to the specific treatment options documented on the POLST form.\textsuperscript{81} Although Dr. Hammes does not mention palliative care or hospice services, one might infer that conversations will also include practitioners from these fields.

Health professionals and the volunteers they engage nevertheless needed to build additional skills and competence to facilitate good quality conversations about care preferences. “In LaCrosse…”, Hammes notes, “…this reality led to the creation of a new role in healthcare: an advance care planning (ACP) facilitator.”\textsuperscript{82} ACP facilitators were typically staff who already have professional skills, who would have 30 to 90 minutes available to engage in conversations, and who work as part of a team with the patient’s physician as a central member.\textsuperscript{83}

Although the physician is a key member of the care team, the Respecting Choices model does not rely on access to physicians to facilitate ACP: the care planner and the designated surrogate lead decision making if the patient loses decisional capacity. Linda Briggs, the associate director of the Respecting Choices team who is responsible for curriculum development, finds that while there is a tendency to assign ACP to the patient’s physician, such

\textsuperscript{79} Ibid.
\textsuperscript{80} Ibid.
\textsuperscript{81} Ibid.
\textsuperscript{82} Ibid.
\textsuperscript{83} Ibid.
an approach is “unsustainable and unreliable” when it comes to implementing ACP as part of the care routine.\textsuperscript{84} Most physicians involved in the Respecting Choices program recognized the importance of ACP conversations, but admitted they rarely had the time to do this consistently with patients and tended to do so only with patients at a high risk for complications.\textsuperscript{85} Briggs cites increasing demands on physician-dependent services and complications with respect to reimbursement as reasons physicians should not be the primary professional charged with ACP.\textsuperscript{86}

The Respecting Choices model was able to mobilize and train volunteers, which, while admirable, renders this approach less feasible in more resource-strapped communities. Yet, the results ought to motivate health care institutions to see the benefits of ACP, and consider including it as a key service. It would be far less likely that someone would be in the unenviable position of trying to articulate their care preferences in the ED if they had already been working with a care planner. Successful care planning would increase the likelihood of having a reliable surrogate, or perhaps even a network of surrogates, thus supporting patients’ agency in decline. Supposing someone was already in stages two or three of the model, they may have access to a nurse help line or hospice services who could help them through critical incidents without requiring them to leave home. Care planning does not necessarily guarantee that the clinicians who will act according to one’s interests will be there at the time of the initial emergency, but there is a far greater chance they will be brought into the loop as conditions deteriorate. As Bernard Hammes pointed out, simply having the conversation allowed each person to start


\textsuperscript{85} Ibid.

\textsuperscript{86} Ibid.
collaborating with potential surrogates and clinicians to be better prepared for life changing emergencies.

Returning to the concept of boundaried agentic holding, the LaCrosse model was better able to respect and accommodate the nuances of the dying process than the health care system as it stands. Because volunteers engaged with patients at various junctures throughout the lifespan, they were better able to gauge when to transition from aggressively holding on to life to sustaining someone in their values and preferences in the end. Volunteer care planners attended to the boundaries of their charges, working to include the friends, relatives, and members of the care team that patients trusted and wanted to involve. Practical boundaries regarding inappropriate and unwanted treatments were at least explored, despite the impossibility of fully anticipating every turn of a disease progression. Edmund, armed only with a singular advance directive and Charlie by his side, could have been much better supported by the health care system. The final section will conclude by imagining how ACP could have given Edmund a more appropriate death.

**Conclusion: Edmund’s Alternate Ending**

Although Lindemann tells us that Edmund did fill out the Declaration of a Desire for a Natural Death, this document alone was not enough to save him from the kind of death he did not want. Conversations which more clearly established alliances with friends and care providers was needed to hold him through the dying process. It is not clear whether Charlie was Edmund’s designated surrogate, which would have given him the legal authority to insist Edmund be taken off the ventilator and allowed to die. However, this is not necessarily Lindemann’s point: she is arguing instead that Charlie is practicing a morally valuable form of holding by defending the character and preferences he had before he was debilitated by the heart attack. What if Edmund
and Charlie had the support and guidance required to connect with clinicians who could have responded in ways that better conformed to what Edmund wanted in the end? I will conclude by imagining how Edmund’s story might be different if he had access to care planning along the lines of Respecting Choices.

It is not clear whether Edmund knew he might be suffering from heart disease, so it is difficult to say whether he might be in the first or second stage of the Respecting Choices model. The first stage, once again, is geared toward designating a POAHC and settling on specific instructions for what to do when the person loses decisional capacity and life sustaining treatments may be inappropriate. But, even if Edmund were only engaged through this first stage of ACP, he could have designated Charlie his POAHC; giving Charlie some leverage over health care practitioners who want to proceed counter to his wishes. They could have been prompted to have a more nuanced conversation about what interventions Edmund would have found particularly objectionable and in what circumstances. In fact, some of these preferences are present in the Declaration document, which stipulates that Edmund did not want artificial nutrition or hydration if he is suffering from a “terminal or incurable” condition. His care team went ahead with artificial nutrition when he was probably too sick to consent, and treatments only intensified from that point.

Even if Edmund was only in this first stage of care planning, he could have specified that he found these treatments objectionable just on the basis of his being eighty-five years old, or because they contravene important values he may have. The disagreement between Dr. Stoddard and Charlie hinges on whether Edmund’s condition is “terminal or incurable”, but this standard did not have to apply. Although this would be more likely to occur in stages two and three of Respecting Choices, Edmund could have designated himself “do not resuscitate” or DNR, and
specified that he is to have comfort measures only in the case of an emergency. He could also have made connections with visiting nurse teams or hospice services that might be able to come to him in the case of a critical episode.

Furthermore, if Edmund knew he had heart disease, he and Charlie could have proceeded according to the second part of the Respecting Choices model. This involves disease-specific planning and anticipation of complications that would alter the goals of care. They could consider the possibility that Edmund could have a heart attack, and anticipate how they might respond. Edmund was able to call Charlie to let him know he was short of breath and having chest pain. Perhaps that would have been his first call, and then Charlie could call ambulatory care for Edmund. There is a chance they could have stabilized him in his home, or at least allowed him to die in the way he wanted. The care planning process could help them anticipate what to do in specific instances, and involve practitioners that could respond in ways that prioritize Tosca-Edmund over Patient-Edmund.

Instead of playing his favorite music for him while he is barely conscious in the hospital, Charlie and Edmund could have spent Edmund’s final hours listening to music at home with Tosca. This outcome is not necessarily elusive or hard to achieve: it just requires better acknowledgement of the network of people needed to support agency in decline, and anticipations of how to proceed in emergencies where someone risks becoming non-decisional. An acute-care oriented health care system tasked with holding on to life is not up to this challenge without significant redesign, and patients cannot necessarily set boundaries on their own without guidance and support. Care planners who can practice boundaried agentic holding, engaging with each person to try to prevent intolerable, wild deaths should be integrated into health care provision and compensated for this morally valuable work.
CHAPTER SIX
A VERY EASY DEATH
RECOGNITION AND LETTING GO AT END OF LIFE

Introduction

The previous chapter treated a hypothetical case in an attempt to show the value of the ACP process. In this chapter, I will turn to Simone de Beauvoir’s autobiographical work about her mother’s dying process: A Very Easy Death. In this text, Simone’s mother Françoise dies painfully and unaware of the fact that she is dying, while Simone and her sister Poupette are in the unenviable position of making her last days as tolerable as possible without traumatizing her further. Simone de Beauvoir argues that she betrayed her mother in her dying process, although her actions were generally in service of her mother’s flawed value system. One might view this as Simone’s being complicit in sexist, patriarchal tendencies endemic to the health care system; tendencies which consigned her mother to a painful, humiliating death where she was often treated as an experiment by her doctors. Violating and heartbreaking as this was to Simone, her loved ones, and her readers, I argue in this chapter that she nevertheless succeeded in holding Françoise through a dying process which accorded to her mother’s values. Although she had to let go of her mother’s capacity for agency, Simone and her sister managed to protect her from a death Françoise would have found intolerable.

The first section of this chapter addresses three additional concepts at work in Hilde Lindemann’s account of holding: misfiring recognition, letting go, and infiltrated consciousness. These operate at the level of what Lindemann calls identity work, but each one is of value to the
advance care planning process as well. Infiltrated consciousness in particular hijacks a person’s capacity to take ownership of one’s needs and desires, cutting off the possibility of their meaningful participation in ACP. Section two traces the narrative of *A Very Easy Death*, arguing that we ought to understand Françoise as suffering from an infiltrated consciousness. Much as it would seem that one ought to bolster a loved one’s agency by simply persuading them out of their flawed value system, or forcing them to abide by values which are more connected to their capacity to thrive, Françoise’s situation reveals that sometimes this is impossible. Rather, if these actions were taken by her loved ones, they would consign her to more suffering that she already stands to face if she is allowed to die according to her flawed preferences. *A Very Easy Death* demonstrates that death is rarely easy in real life, and is punctuated by complex processes of recognition and letting go.

**Other Operations in Identity Work: Misfiring Recognition, Letting Go, and Infiltrated Consciousness**

Holding someone in a particular, personal identity is a dynamic, interactive process according to Lindemann, and this process is often reciprocal.¹ The identity conferring narratives one might share with another person can be mutually reinforcing, or the aspects of identity which are lost or rejected can produce corresponding effects in the related person. Lindemann notes that relationships such as teacher-student, parent-child, and doctor-patient are all examples where expectations and narratives on one side generate corresponding expectations and narratives on the other.² We expect a parent to feed their child and help them navigate what I will refer to in the next chapter as ‘activities of daily living’ or ADLs, while helping them become self-reliant in these tasks. We expect children to follow their parents’ guidance until they are able to take over

---


² Ibid.
these activities on their own. Meanwhile, children ought to be able to trust that their parents are helping them develop in ways which will ultimately be to their benefit, while parents have a reasonable expectation that their children will follow their guidance. The forms of holding and letting go that inform these interactions tend to reinforce one another, and produce shared social expectations.

The reciprocity characteristic of deeper forms of identity work is of paramount importance to the advance care planning process. A person attempting to solidify their network of surrogate decision makers needs to be aware of who will navigate their preferences in the way that is right for them: who will hold them to their values, and who will accommodate their shifting preferences if they feel it causing avoidable suffering. Although I agree with Lindemann that the preferences a person held when they had fullest agency should take priority; in the end, a “good” choice is still somewhat relative. Returning to the Lazaroff example from Chapter three, we cannot necessarily concede with Gawande that Lazaroff dies an intolerable death: that Gawande should have been able to paternalistically refuse him further treatment. As Lindemann points out, if Lazaroff had always been an observant Orthodox Jew who believed that God commanded his people to uphold the sanctity of human life, it would seem disrespectful of his son David to make a mockery of one of his father’s most deeply held, lifelong commitments by letting him stop rather than supporting him through an onerous course of treatment. This chapter will argue that Simone de Beauvoir is in a comparable, tragic position with respect to her mother: she is forced to hold her mother through the dying process while accommodating her mother’s preference of deferring to patriarchal and medical authorities. She holds her mother in

---

3 Ibid., 191.
her values, but is in the heartbreaking situation of having to let go of any agency her mother had left.

The most common reason that efforts to hold someone in their identity go wrong is that the stories by which that person is recognized are inaccurate.\(^4\) As I discuss in Chapter two, master-narratives which portray certain groups as inferior do damage to members’ agency and character. This must be undone with alliance-building through participation in communities of choice and counterstories. Failures of recognition occur commonly enough for more personal reasons as well;\(^5\) perhaps especially between parents who must navigate the expectations they have for their children, and young people who are struggling to craft their own identities. As much as recognition can “misfire” at a socio-political level, “misfiring recognition” is also a common feature of relationships within the family. For example, Simone de Beauvoir describes her mother’s inability to properly recognize her in *A Very Easy Death*. As a young adult studying philosophy, it occurs to Simone she no longer believes in God and she lets go of her identity as a Catholic.\(^6\) This sends her mother, Françoise, into despair and she asks their relatives and friends to pray for Simone.

Initially Simone experiences grief over this lost part of herself, until it occurs to her that her mother is crying primarily over her own failure to instill a particular identity in her daughter. The fact that her mother asks others to pray for her rather than simply extending her own sympathy to Simone shows that Françoise was overly invested in others’ perception of the family as good, upstanding Christians. If Simone is at peace with her rejection of faith in favor of

\(^4\) Ibid., 109.

\(^5\) Ibid., 112.

\(^6\) De Beauvoir, Simone. *A Very Easy Death*, 67-8. All further references to Simone’s lost faith are to these pages in the text.
secular humanism, it seems her mother ought to be able to “let go” and accept her daughter’s newfound identity. Instead, Simone remarks, “…how could she accept me when she avoided looking into her own heart.” Furthermore, until *She Came to Stay* came out, “…she knew almost nothing of my life.” Françoise’s ability to recognize her daughter is misfiring, and she seems unable to let go of the now-irrelevant identity construct.

“Letting go” can function in the service of maintaining someone in their personhood and identity, such as when a parent does manage to accept their child’s loss of faith, but it can also represent a deliberate refusal to hold someone in an important aspect of their identity.⁷ As an example of the latter, Lindemann shares the story of a young actor and his father who are attending a cast party after the father came to see his son act in a play.⁸ Potentially inebriated but clearly resentful, the son takes his father to task for not supporting his acting endeavors. This would appear to be one of few performances the father has attended, and the son calls him out publicly at the party. The father wants to project himself as a decent dad, but his son “lets him go”: refusing to hold him in an important and contextually relevant part of his identity, and magnifying the humiliation by letting him go in front of strangers.⁹ Thus, much as letting go can be of moral benefit and strengthen a relationship, it can also do moral damage and compromise a relationship.

Once again, Françoise does not want to let go of a particular version of her daughter’s identity: it seems she was overinvested in the reciprocity they might have shared as members of a faith community and the social roles which go along with it, to the detriment of a more authentic

---


⁸ This anecdote opens the Chapter “Ordinary Identity Work” in *Holding and Letting Go*, pgs. 95-97. I will retell relevant aspects briefly throughout this paragraph.

⁹ Ibid., 105.
relationship. Simone found Françoise controlling and intrusive as a parent: she would take great
care on her and her sister’s behalf, which was what supposedly justified her tyranny.¹⁰ When she
would intrude on her daughters, she would justify her actions by claiming: “I certainly have the
right”.¹¹ Simone finds this justification to betray a lack of self-assurance in the legitimacy of her
desires: if Françoise thought her involvement was legitimate she would just act.¹² In Simone’s
view, Françoise had never been taught to see her own motives clearly or use her own judgment.¹³
She had to take shelter behind authority, but the authorities she respected tended not to be in
agreement: e.g. Françoise’s mother superior and her philandering, spendthrift husband.¹⁴ So, she
“…repressed her appetites and lived in self-denial”, although Simone suspects there was
someone “full-blooded and spirited” living “deformed and mutilated” inside of her.¹⁵

Lindemann addresses this phenomenon as well, describing it as how an agent’s
consciousness can become “infiltrated”. Oppressive master narratives which enter into social
group identities often entail that what members of oppressed groups say and do tends not to get
the right response from the dominant group.¹⁶ It is not that people in stigmatized groups cannot
speak or act in ways that would reveal their mental states, the problem is that their oppressors
refuse to acknowledge their right to have those states.¹⁷ Over time, this erodes a person’s agency

¹¹ Ibid., 39.
¹² Ibid.
¹³ Ibid., 41.
¹⁴ Ibid., 42.
¹⁵ Ibid., 43.
¹⁷ Ibid.
and self-trust, impacting the ways they engage in the world. Arguably, Françoise’s agency as a woman, spouse and mother had been thwarted by oppressive social forces. This is perhaps most evident in her dying process, throughout which she is even deprived of the knowledge that she is dying.

The advance care planning process ought to take into consideration processes of misfiring recognition, the evolution of letting go in a person’s life, and the problem of infiltrated consciousness as it guides people through the unique constellation of arrangements that will allow them to die an appropriate death. Each of these ideas of Lindemann’s impacts the decisions a person might make about who they want involved in their care or who they want to decide for them. Infiltrated consciousness in particular poses a challenge to the success of the advance care planning process, because it increases the likelihood that a person will not be able to admit to their own needs and desires. Even if someone has experienced racism or sexism to the point where they are cynical about sharing their values, it is still possible to work through significant socio-political alliances to help them identify and meet their needs. Infiltrated consciousness, on the other hand, is particularly insidious because it interferes with a person’s capacity to accurately reflect upon and take ownership of their authentic needs and desires. It is difficult to plan an appropriate death for someone who is deeply out of touch with their own interests. Thus, how the ACP process ought to cope with the problem of infiltrated consciousness may not necessarily have a uniform solution.

_A Very Easy Death?_

“I pictured Maman, blinded for hours by the black sun that no one can look at directly: the horror of her staring eyes with their dilated pupils. She had a very easy death; an upper-class death.”

18 De Beauvoir, Simone. _A Very Easy Death_, 95.
"A Very Easy Death" is Simone de Beauvoir’s retelling of the events surrounding her mother, Françoise’s, death. This section will provide an overview of the narrative, and give further detail on why we ought to understand Françoise de Beauvoir as suffering from infiltrated consciousness. For the most part, her doctors are cruelly paternalistic, and it is among the tragedies of the narrative that none of them care about giving their patient an appropriate death. Yet, it also seems that Françoise would not have wanted to know she was dying: it is clear she had an “animal” fear of death, from which Simone and her sister want to protect her.\(^1\) Prima facie, it may seem that protecting her would mean persuading her against further treatment. However, my tracing of the events surrounding Françoise’s death should begin to cast doubt on the idea that this is necessarily the right approach. In holding, Lindemann claims that we are tasked with balancing the duty to persuade with the duty to prevent a loved one’s suffering.\(^2\) As noted in Chapter three, she relies on Eric Cassell’s more expansive definition of suffering, which includes violations to one’s value system as much as physical suffering. Thus, in considering whether Françoise ought to be persuaded or allowed to continue according to her preferences, we are forced to consider how much she stands to suffer if her daughters contravene her wishes.

The narrative begins in October of 1963 with Simone receiving a call from a friend who lived in the same building as her mother: Françoise had fallen and was eventually discovered by a neighbor.\(^3\) She crawled for two hours to reach her telephone, and managed to call a friend to wedge her door open. Another neighbor, a “woman doctor”, diagnosed Françoise with “a fracture of the neck of the femur”. Françoise spends the night in the public ward of a local

\(^1\) Ibid., 14.


\(^3\) The initial story of Françoise’s fall takes place in *A Very Easy Death*, pages 9-10. For longer exchanges, I will abbreviate this text as “AVED” and provide the page range.
hospital, but Simone’s friend makes plans to take her to a nursing home with an association with a renowned bone surgeon. Françoise falls October the 24th, spends roughly six weeks in the nursing home, and dies in the early morning December the 4th.\textsuperscript{22} It was not complications from the fall which ended her life, however. An exploratory surgery reveals she has bowel cancer roughly a week into her nursing home stay,\textsuperscript{23} although at no point do the doctors explain their concerns or justify the need for the operation to her. Françoise is not even told she has cancer. Culturally, medical paternalism was at its height in mid-20th century Europe and the U.S., and most of Françoise’s doctors are clear examples of it.

Among the tragic aspects of the narrative is that Simone de Beauvoir, a philosopher known for her analysis of sexism and the damage inflicted on women’s agency as a result of gender socialization, is compelled to watch her own mother die in a way that violates the sense of agency she wanted to facilitate among women with her writing. Françoise is never aware of the fact that she has cancer, and is not in a position to be able to accept that she is dying at the age of 78 despite not showing signs of dementia. Throughout the narrative Françoise is led to believe that she is healing from the fall and peritonitis; she “confused her last days with convalescence”,\textsuperscript{24} Simone reflects, while Simone and her sister undergo “six weeks of intimacy rotted by betrayal”.\textsuperscript{25}

It is Simone who consents to her mother’s operation, although there was no reason to consider Françoise non-decisional or avoid seeking her consent.\textsuperscript{26} One of the nurses, Mme

\textsuperscript{22}De Beauvoir, Simone. \textit{A Very Easy Death}, 86.

\textsuperscript{23}Ibid., 26.

\textsuperscript{24}Ibid., 100.

\textsuperscript{25}Ibid., 96.

\textsuperscript{26}Simone’s consent and the exchange with Nurse Gontrand take place in AVED from pages 28-29.
Gontrand, warns Simone not to consent to the procedure and then claps her hand to her mouth: how horrible it would be if the doctors knew I warned you, she says, although she could not help but speak “...as though it were her own mother.” When the surgical team recommends the operation, Simone agrees to it knowing that Françoise would likely only have three days without intervention. Mme Gontrand’s warning “[d]on’t let them operate on her” refrains in her thoughts: “[a] frail argument” against the decision of a specialist; a frail argument against my sister’s hopes.”

In her own estimation of her actions, Simone de Beauvoir feels that she failed and betrayed her mother in death. After the procedure, when it is clear that Françoise still thinks she is just suffering from peritonitis, Simone remarks that the betrayal was beginning.\footnote{Ibid., 45.} For the most part, Françoise’s doctors are demeaning and patronizing. Simone arrives one morning to find Dr. N, a “resuscitation expert”, about to place a nasogastric tube into her mother.\footnote{The incidents surrounding Dr. N’s placement of the NG tube take place in AVED pages 27-28.} She chases him down: “[w]hite coat, white cap: a young man with an unresponsive face. “Why this tube? Why torture Maman when there’s no hope?” He gave me a withering look. “I am doing what has to be done” he says, and proceeds to place the tube while Simone is not let into the room. When she does come in, she finds her mother’s face had shrunken even more: “it had the saddest air of submission.” Dr. N is haughty and demeaning: after the tube managed to drain some of the fluid from her he says “Would you like me to have left that in her stomach?...At dawn she had scarcely four hours left. I have brought her back to life.” Simone does not reply, but thinks “[f]or what?” One specialist is somewhat kinder: “[Dr. P] did not assume consequential airs; he talked...
to Maman as though she were a human being and he answered my questions willingly.” Dr. N on the other hand was “…smart, athletic, energetic, infatuated with technique, and he had resuscitated Maman with great zeal; but for him she was the subject of an interesting experiment and not a person.”

Françoise dies painfully and without a full understanding of what is happening to her. It seems Simone is right to reproach herself for failing to protect her mother from being treated like an experiment when she is vulnerable and dying. At one point, Simone reflects that she too has a cancer eating into her: remorse. When she would hear of sick people undergoing a long martyrdom, she found herself indignant at the apathy of their relatives; she would kill them before letting them suffer. Yet, when put in this situation herself, she finds she has abjured her own ethics and was “…beaten by the ethics of society.” On the contrary, her companion Sartre replies: she was not beaten by society but by “technique”, which was “fatal.” Simone agrees: “[o]ne is caught up in the wheels and dragged along, powerless in the face of specialists’, diagnoses, their forecasts, their decisions. The patient becomes their property: get him away from them if you can!”

Yet, it is clear throughout the narrative that Françoise does not want to admit to herself or her daughters that she is dying. She likely would not want full comprehension of the state of her illness such that she could deliberate about possible courses of action. At one point Simone and her sister Poupette are both present at Françoise’s bedside, and she gets suspicious they are both there because she may not have much time left. They each dismiss her fear, acknowledging

---

29 Simone’s comparisons of Dr. N to Dr. P take place in AVED pages 51-52.

30 Simone’s reflection on her remorse and conversation with Sartre takes place on page 57 of AVED.

31 Simone and Poupette’s decision to foster their mother’s hope takes place on page 66 of AVED.
implicitly that “hope was her most urgent need.” Françoise has a recurring nightmare where she is being chased: she runs and runs, and comes up against a wall.32 She has to jump over the wall, but she does not know what is on the other side and is terrified of whatever could be there.

“Death itself does not frighten me;” she says, “it is the jump I am afraid of.” At the same time, Simone observes that “…she clung ferociously to this world, and she had an animal dread of death.” In the last moments of her life, Françoise struggles to articulate the words that “[w]e must…keep…back…desh.”, to which Simone replies “[w]e must keep back the desk?”33 “No,” Françoise replies strongly, “Death”, adding “I don’t want to die.”

Reflecting on the situation after her mother’s death, Simone recognizes that Françoise has always been afraid of having cancer, but that after the operation she never thinks about it.34 Françoise believes the doctors regarding her peritonitis diagnosis, although peritonitis was merely a symptom of her advanced bowel cancer. Had Françoise known she had bowel cancer, Simone believes that she would have passed the end of her life in a potentially 2-3 year state of dread; most likely subjected to radiation therapy with unpredictable results.35 When Poupette is distressed over the fact that her mother died traumatically after a coma, one of the nurses assures her that on the contrary, it was “…a very easy death.”36 The phrase strikes Simone, and it becomes the title of her book (and the introduction to this section). Later on, Simone is able to abstract somewhat from her grief; and compare the way her mother died to the way many other people die:

32 Françoise’s recurring nightmare is described in AVED pages 14-15.
33 The “desh” desk/death conversation takes place in AVED pages 88-89.
34 Ibid., 89.
35 Ibid., 93.
36 Ibid., 88.
For indeed, comparatively speaking, her death was an easy one. ‘Don’t leave me in the power of the brutes.’ I thought of all those who have no one to make that appeal to: what agony it must be to feel oneself a defenseless thing, utterly at the mercy of indifferent doctors and overworked nurses. No hand on the forehead when terror seizes them; no sedative as soon as pain begins to tear them; no lying prattle to fill the silence of the void. ‘She aged 40 years in twenty-four hours.’ That phrase too had obsessed my mind. Even today—why?—there are horrible agonizing deaths. And then in the public wards, when the last hour is coming near, they put a screen round the dying man’s bed: he has seen the screen round other beds that were empty the next day: he knows. I pictured Maman, blinded for hours by the black sun that no one can look at directly: the horror of her staring eyes with their dilated pupils. She had a very easy death; an upper-class death.

There are undeniably better and worse ways to die, and Françoise was fortunate to have two daughters to be present with her throughout the process. It would be a much more painful process to have to rely solely on indifferent doctors and overworked nurses; to have them pull the curtain or put up a screen so that the other patients can avoid the trauma of watching one die and to know that death is impending.

Elsewhere in *A Very Easy Death* Simone de Beauvoir claims that there is no such thing as a natural death, and that even when someone knows they are dying and consents to it, death is still an unjustifiable violation. Yet this must be balanced with the recognition that some deaths are less painful and more tolerable than others. As should be clear from the first chapter of this dissertation, the COVID-19 pandemic has forced tens, potentially hundreds of thousands of people to die alone and isolated in health care institutions. It is irresponsible and morally wrong not to try to think of ways this objectionable outcome could have been avoided, and in the end, I suspect she would agree. Death presents the opportunity for living friends, relatives, and caregivers to think about how they will attend to their loved one in their last moments. Simone and Poupette were able to hold their mother through a dying process which accorded to her

---

37 Françoise makes this plea to Simone and Poupette when she does not like the Sunday nurses, and she wants her daughters to stay to ensure she is not treated roughly.

38 Ibid., 94-5.

39 Ibid., 106.
values, although the experience was undeniably traumatic for them. It is a significant good that
Simone and her sister could be present to support their mother, although their experience forces
us to consider the ways Françoise could have died a more tolerable death.

Françoise’s choice to blindly trust in her doctors and thus undergo surgery and its
painful aftermath is not an enviable choice, and it might be hoped that physicians today would be
less cruelly invested in their own technique than Dr. N. It is also questionable whether Françoise
is capable of making an autonomous choice with good relational support for her own agency.
Again, Simone says of her mother that “[s]he had not been taught to see her own motives plainly
nor to use her own judgment. She had to take shelter behind authority: but the authorities she
respected were not in agreement; “there was hardly a single point in common between the
Mother Superior of Les Oiseaux and my father.”40 Françoise’s agency and capacity for self-
determination are stunted, and she is unable to decide for herself when to disregard or disobey
authority: “[i]n her childhood her body, her heart and her mind had been squeezed into an armor
of principles and prohibitions. A full-blooded, spirited woman lived on inside her, but a stranger
to herself, deformed and mutilated.”41 At this point in her life, Françoise may not be able to
discern her true preferences. She seems to be a suffering from what Lindemann describes as
infiltrated consciousness.

What kind of responsibility do Simone and Poupette have toward their mother given her
infiltrated consciousness? How far are they obligated to respect her cares, namely her preference
of going along with her doctors’ plans for her and her unwillingness to come to terms with her
own mortality? Is she a marginalized agent in Jaworska’s sense? Would they then have the duty

40 Ibid., 41-2.
41 Ibid., 43.
to persuade her against a course of action which will result in uncontrollable, pointless suffering?
The next section will defend Simone’s course of action on the grounds of these key concepts, arguing that despite the suffering involved, she succeeded in holding her mother in death. Simone was forced to let go of her mother’s capacity for agency, but she held her in her personhood throughout the dying process.

**The Duty to Persuade and the Appropriateness of Misshapen Response**

As I explored in Chapter three, Lindemann argues that loved ones involved in identity work may have a duty to persuade. “Perhaps it’s when we are dying that we need most to be held—even coercively held—in our identities, that others may ratify the goodness of our lives and being, and keep us in that goodness.” she argues. The trouble for Simone and her mother, however, is that Françoise’s values are liable to cause her undue suffering, while her infiltrated consciousness will make it difficult to persuade her to consider other courses of action. Françoise is decisional by conventional health care standards, and having infiltrated consciousness is not enough to qualify her as a marginalized agent in Jaworska’s sense. It is doubtful that Simone or Poupette could have persuaded her against medical advice; meanwhile, it is among the tragedies of this narrative that none of the doctors seem at all concerned with helping their patient achieve an appropriate death.

Lindemann also suggests that sometimes a “misshapen response” is appropriate for agents who might be suffering from infiltrated consciousness, or in cases where one set of duties is superseded by another. Misshapen response may be appropriate because the initial duties relied too heavily on social power constructs, or more simply because someone involved in the

---


43 Ibid., 116.
interactions of holding or letting go is unaware or uninformed. For example, Lindemann references a story of Michael Walzer’s regarding George Orwell. In the 1930s, Orwell served as a soldier fighting against the Facists in the Spanish Civil War. During an air raid, Orwell saw an enemy soldier jump out of a trench and run along the top of a parapet, holding up his trousers with both hands as he ran. Rather than do his duty and shoot him Orwell let him go, remarking that “I had come here to shoot at ‘Fascists’; but a man who is holding up his trousers isn’t a ‘Fascist,’ he is a visibly fellow creature, similar to yourself, and you don’t feel like shooting at him.” If Orwell had killed the enemy soldier, he wouldn’t have killed him in his full capacity and identity as a soldier. It would be literally shooting someone in the back. Thus, a misshapen response which dispenses with some arguably more surface duties can be morally appropriate.

So, perhaps on the basis of her deeper care for her mother, Simone de Beauvoir should have had a comparable misshapen response. Maybe she ought to have forced her mother to leave against medical advice and insisted the doctors provide her with enough morphine so that Françoise could die at home. Yet, given that Françoise does not know or want to admit she is dying, she would probably be traumatized by this gesture. If Simone and Poupette had been honest with her about her diagnosis of advanced bowel cancer, the truth would probably have caused her more distress than the omission. Practically speaking, if they tried to have her discharged, they would have had to independently hire nurses to care for her and administer medications, and she might face more anxiety and uncertainty without the resources of the hospital.

---

44 Ibid., pgs. 116-17. All references in this paragraph are to these two pages.

With her infiltrated consciousness, Françoise would have probably have objected to a non-medicalized death: “[a]ll that matters is that the doctors are pleased” she says when her health temporarily improves after the surgery.\textsuperscript{46} She expresses a desire to continue on with painful injections after her surgery, and is delighted to find out that the doctors are using her as an “advertisement” of their skill to other patients.\textsuperscript{47} Knowing that she had limited time, Simone and Poupette are in the unenviable position of trying to make her final days as tolerable as possible. Françoise would stand to suffer more if they responded more actively, or tried to fill in the gaps of her agency with ideals of their own—even though these are more likely to be connected to a person’s capacity to live well.

Furthermore, if Simone and Poupette were to force Françoise to die in accordance with their (arguably better) value system, they would be forcing her to die against her own values. When we know that throughout her life Françoise consciously prioritized the appearance of social status and obedience to medical authorities over her own physical and emotional wellbeing, and we know that she is unlikely to be persuaded otherwise, and given the fact that she has limited time left to live, it seems wrong to force her to die in a way we might consider to more appropriate. She would suffer more if she were made to die against her value system, physically and in Cassell’s more expansive sense. A misshapen response is not likely to strike a better balance with respect to the need to minimize suffering in this case.

\textbf{Conclusion}

The temptation upon reading \textit{A Very Easy Death} is to assure oneself that advances with respect to patient rights and greater consideration of agency and autonomy would prevent what

\textsuperscript{46} De Beauvoir, Simone. \textit{A Very Easy Death}, 71.

\textsuperscript{47} Ibid., 55.
occurs between Simone de Beauvoir and her mother, Françoise, to happen today. We expect that social changes since the 1960s would initiate corresponding shifts in the health care system; that thanks to movements for gender justice doctors would be more empathic and that nurses would be better compensated and more respected in the process of providing care. Some shifts in this direction have occurred, at the same time that growing socio-economic inequality has strained the health care system further.

However, the COVID-19 pandemic has demonstrated that our strained system is still not equipped to help people manage their dying process. Doctors are unable to support their patients not necessarily because they are chauvinistic and inclined to treat their patients like science experiments, but because they have too many to attend to in too little time. Comparable pressure applies to nurses, who must cope with patients’ psychosocial distress and the effects of isolation restrictions. Meanwhile, more patients than ever before were condemned to die institutional deaths like the ones which moved Simone de Beauvoir: with “[n]o hand on the forehead when terror seizes them; no sedative as soon as pain begins to tear them; no lying prattle to fill the silence of the void…”48 The socioeconomic injustice and other circumstances that lead people to die in this way were compounded by the crisis standards of care implemented during the pandemic.

Once again, the previous Chapter “Why Practice ACP: A Case for Holding”, treated a hypothetical case in an attempt to show the value of the ACP process. Therein, I argued that better investiture in Edmund’s relational network would have helped him avoid the unenviable death he suffers. He could have been connected with mobile nursing and consultation services, perhaps he could have been stabilized at home and avoided the hospital altogether. In contrast to

48 De Beauvoir, Simone. A Very Easy Death, 94.
my re-writing of the Charlie and Edmund example, *A Very Easy Death* shows how tortuous the dying process can be. It is not merely a question of identifying who might be among a dying persons alliances and making sure treatment limitations are indicated on the relevant forms. Even when friends or relatives are holding one another in functional ways, infiltrated consciousness can prevent some people from meaningfully engaging with the reality that their lives will end. Being forced to let go of a certain kind of reciprocity during the dying process is painful, although I maintain that earlier conversations about values would mitigate some of this pain. The health care system could also be reconfigured to acknowledge the need for better end of life care planning. An “easy” death is perhaps illusory, but it is equally wrong to be avoid acknowledging all of the forces which make so many deaths intolerable.
CHAPTER SEVEN
CARE WORKERS AS CARE PLANNERS

Introduction

Particularly at end of life, providing good care for a loved one or in a professional capacity requires sensitivity and an awareness of what creates meaningful quality of life. This chapter proposes that direct care workers’ practice gives them enhanced insight into the kinds of considerations that make chronically ill and dying people’s lives meaningful. Although it would be a conflict of interest for care workers to have care planning conversations with their own patients, their skills would help them ask the right questions and guide clients in planning treatment if they did train and become certified to work in an additional capacity as advance care planners. Direct care workers’ (DCWs) success on the job is tied to their ability to attend to quotidian concerns with respect to their patient’s variable agency, with the goal of making life as tolerable and potentially meaningful as possible.

The first section of this chapter describes direct care workers and the kind of work they do. Despite being some of the most undercompensated and underappreciated health care providers, care workers’ success entails constant coping with the boundary between overtreatment and neglect in intimate interactions with their clients. Rather than a disadvantage, this positions them to be able to ascertain and prioritize what can be done to enhance agency and quality of life when resources are scarce. If we aim to avoid a crisis response to care and unnecessary institutionalization, care workers should be integrated into the health care system in
ways that help older and chronically ill people set meaningful boundaries about the care they want to receive.

The second section of this Chapter, “Why Direct Care Workers Ought to Be Involved in Advance Care Planning: A Practical Justification”, gives a practical proposal for how to involve direct care workers in ACP that would be of mutual benefit to care workers and recipients. Given that standards for reimbursement for care work are somewhat ambiguous while standards for reimbursement for ACP are comparatively clear, I argue that allowing care workers to recertify as ACP facilitators would enhance their income and professional status. The third section of this Chapter, “Why Direct Care Workers Ought to Be Involved in Advance Care Planning: A Moral Justification” addresses the moral status of care provision. In some ideal instances, care workers can become fictive kin to their charges. This is a morally valuable relationship that can provide job satisfaction to some care workers, but it is not a substitute for the greater social responsibility to recognize that care workers equally have care needs. Following Eva Kittay’s theory of connection based equality, I propose that employing care workers as care planners allows them to repurpose their skills in ways which help them meet their own needs, and which contribute to healthier dependency relationships throughout society.

**Direct Care Workers (DCWs) and the Impact of the Pandemic on Direct Care Work**

Direct care worker is a general term for workers who provide essential support services to disabled and older adults, although it can also refer to specific job categories in programs or institutions. The direct care workforce is already sizeable, but it is expanding rapidly as more

---

1 Stephen Campbell et al., *Caring for the Future: The Power and Potential of America’s Direct Care Workforce*, 4.
Americans grow older, live longer with disabilities and chronic conditions, and there are fewer available family caregivers to care for them.\(^2\) There are roughly 4.6 million DCWs in the U.S. as of 2021, with 2.3 million employed as home care workers.\(^3\) Home health is the largest employment sector for DCWs, although approximately 700,000 work in residential care homes, 580,000 work in nursing homes, and 900,00 work in hospitals.\(^4\) According to PHI, which is among the nation’s leading authorities on the direct care workforce, in the decade between 2009 and 2019 the DCW workforce grew by 52%.\(^5\) By 2028, they estimate the U.S. will need an additional 1.3 million workers.\(^6\)

DCWs take on an exceptionally broad scope of responsibilities, often with little support from the organizations who employ them. Their tasks are typically divided into “activities of daily living” or ADLs, and “instrumental activities of daily living” or IADLs.\(^7\) MD and MPH Leslie Kernisan characterizes ADLs as skills we learn as young children, and IADLs as skills we learn as young adults or adolescents.\(^8\) ADLs often include walking around or outside one’s home, being able to feed oneself, getting to and from the toilet and cleaning up afterward, bathing, and transferring from one position to another: often from a bed to a chair with assistive

\(^2\) Ibid., 6.

\(^3\) Ibid.

\(^4\) Ibid.

\(^5\) Ibid., 18.

\(^6\) Ibid.


\(^8\) Ibid.
devices such as a walker. How much assistance each client or patient will need with their ADLs is often ambiguous, and can vary from day to day. Some may require full assistance from their caregiver, which can involve lifting someone from their bed or chair to the bathroom multiple times over the course of a shift. IADLs can involve tasks as complicated as managing one’s finances, driving, shopping and meal preparation, cleaning one’s home, and procuring and safely taking medications. These are also nuanced responsibilities, which require good judgment in addition to compassion, sensitivity, and physical adeptness.

Low-income women and people of color make up the majority of DCWs, and the workforce relies heavily on immigrant workers. 86% of DCWs are women, with a median age of 41. Only 14% of DCWs are men. In home care, the median age of workers is 46 and the workforce is older overall: 30% of home care workers are ages 55 and older, while only 11% are 16-25 years old (the youngest cohort measured). People of color, including Black, Latinx, and Asian/Pacific Islanders make up the majority of DCWs, over 30% of whom identify as Black or African American. Approximately one in four or 26% of DCWs working in home care settings was born outside the United States, but some authors speculate that if this included workers who were privately hired to care for older and disabled people, the number would be much

9 Ibid.
10 Ibid.
11 Stephen Campbell et al., Caring for the Future: The Power and Potential of America’s Direct Care Workforce, 13.
12 Ibid.
13 Ibid.
14 Ibid.
15 Ibid.
higher.\textsuperscript{16} There are many practical barriers to measuring the contributions of undocumented workers, namely the risk they take on by responding to surveys, but one might reasonably speculate they are also disproportionately involved in direct care work.

Despite the significant demand for care work, DCWs are grossly undercompensated for the complexity of their responsibilities. Care work stands to be among the most in-demand but poorly compensated services. According to the Bureau of Labor Statistics, the median wage for all direct care workers is only $12.27 per hour, and the median annual salary for all was just $20,200.\textsuperscript{17} Some authors measure the average salary for home care workers specifically at just $16,200.\textsuperscript{18} High rates of part time employment were partly responsible for these measures, with almost half of all DCWs employed part time.\textsuperscript{19} Low wages and lack of benefits mean that many are forced to work multiple jobs and rely on public assistance. 42% of DCWs require some form of public assistance due to low earnings and high poverty rates, with 15% living in poverty themselves and 44% in low-income households.\textsuperscript{20} Many part-time and self-employed DCWs lack health insurance coverage, and rely on Medicaid as well as other public assistance programs including food stamps, housing support, and childcare subsidies.\textsuperscript{21} Structural racism intensifies

\begin{footnotesize}
\begin{enumerate}
\item Zallman, Leah et al. “Care for America’s Elderly and Disabled People Relies on Immigrant Labor,” 919.
\item Stephen Campbell et al., \textit{Caring for the Future: The Power and Potential of America’s Direct Care Workforce}, 16.
\item Stephen Campbell et al., \textit{Caring for the Future: The Power and Potential of America’s Direct Care Workforce}, 16.
\item Ibid
\end{enumerate}
\end{footnotesize}
the strain on Black women workers in particular, who are paid less and forced to rely more on public assistance than other DCWs.²²

The field of home care has yet to fully cope with its origins in the labor of enslaved people, while racist and sexist abuse complicates the work of DCWs today. April Verrett, president of SEIU Local 2015 of California, discusses these issues in a 2020 article entitled “Home Care Workers Are Called Essential. But the History of the Profession Shows that The U.S. Has Never Treated Them That Way.” She points out that modern home care’s origins are in the antebellum South, “…where enslaved Blacks, almost always women, took care of the day-to-day needs of white families.”²³ After the Civil War, the profession of “domestic worker” replaced “slave” or “domestic servant” in the lexicon, but there were scant legal protections for care workers, particularly throughout the Jim Crow era.²⁴ Fair labor standards for domestic workers were not debated in Congress until the 1930s as part of the New Deal, and even then, southern representatives refused to pass protections for workers in majority-Black fields.²⁵ It was not until 1974 that private home care workers were included in the Fair Labor Standards Act (FLSA), but the U.S. Department of Labor interpreted this amendment to exempt them just one year later: deeming private sector home care workers “companions” who are not entitled to

²² Ibid.


²⁴ Ibid.

²⁵ Ibid.
minimum wage, overtime, or paid time off. The 1974 “companionship exemption” of the FLSA still holds today, complicating basic economic justice provisions for these workers.

Gender-based abuse and violence is also frustratingly common for DCWs, especially for those working in private homes. A 2015 study focusing on women working as private caregivers in Oregon found that 61.3% had experienced at least one type of workplace violence over the past year; with 51.5% experiencing verbal abuse, 27.5% coping with workplace aggression by clients, 27.65% being sexually harassed, and 12.8% experiencing sexual aggression. For the purposes of the study, sexual harassment could include being whistled or leered at, being asked personally intrusive questions about one’s sex life, or being propositioned for dates or sex on the job. Sexual aggression could include a client’s disrespect for a worker’s personal boundaries, including being “…pinched, patted, hugged, or had an arm around you in a way that made you uncomfortable.”, which 11.3% of respondents experienced, to being fondled (3.1%), to being physically restrained (1.0%), to being raped (0.3%). Experiencing any form of workplace violence or sexual harassment was associated with greater stress, depression and sleep problems among homecare workers when controlling for age and education. Finally, results of this study were found to conform to other studies throughout the U.S.

26 Ibid.
27 Ibid.
29 Ibid., 7.
30 Ibid.
31 Ibid.
32 Ibid., 11.
To summarize: DCWs receive some of the lowest wages of all health care providers, are more likely to live in poverty and work multiple jobs, are more reliant on public assistance, are more likely to lack job protections due to systemic racism and the legacy of slavery (among other factors), and are more subject to gender-based abuse and violence—all while performing some of the most emotionally taxing and physically demanding work possible. A lack of infrastructure and oversight of home care in particular means that these workers are largely dependent on their own skills and knowledge to keep themselves safe. They also accomplish their work in the face of a general lack of awareness on the part of the general public of the technical and interpersonal skills that DCWs must possess. As legal scholars Blum and Mathis point out, “[l]ow wages and poor training standards serve to reinforce the view that DCWs are unskilled or low-skilled workers.” This public perception compounds the stress and feelings of worthlessness many DCWs contend with on a daily basis.

Furthermore, the onset of the COVID-19 pandemic significantly intensified the pressure on DCWs for a number of reasons. First, they provide intimate personal care for older and chronically ill people who are at high-risk of contracting the virus. This can render them disease vectors if they are caring for clients spread throughout the community, and potentially expose their own families to the virus. Also, DCWs themselves are at higher risk given that

33 Ibid., 10.
35 Ibid.
36 Ibid., 335.
37 Ibid.
most are older than 55 and persons of color.\textsuperscript{38} Although they were classified as “essential workers”, many lacked affordable access to personal protective equipment (PPE) or COVID testing, and felt they were not given adequate information about the virus.\textsuperscript{39} Vaccine distribution tended to favor DCWs in institutional settings rather than those working in the community.\textsuperscript{40} Fears about the virus caused some DCWs to leave the workforce, while others felt they had no choice to keep working even without PPE.\textsuperscript{41} Many continued to work, reporting a sense of duty and obligation.\textsuperscript{42}

Government and federal agencies’ response to the problems faced by DCWs during the pandemic has been inconsistent and even incoherent. On the one hand, the federal Coronavirus Aid, Relief and Economic Security Act (CARES Act) included a pandemic unemployment assistance (PUA) program.\textsuperscript{43} As noted by Bailey Bryant in “Loopholes in the COVID-19 Unemployment Program”: under the PUA program, workers unemployed due to COVID-19 had easier access to a federal cash benefit that could be substantial when joined with a state unemployment payment.\textsuperscript{44} In some cases, caregivers made more money being officially

\begin{itemize}
\item\textsuperscript{38} Ibid.
\item\textsuperscript{39} Sterling, Madeline R. “Experiences of Home Health Workers in New York City During the Coronavirus Disease Pandemic,” 1453.
\item\textsuperscript{40} Blum, John D., and Shawn R. Mathis. “Forgotten on the Frontlines: The Plight of Direct Care Workers During COVID-19,” 336.
\item\textsuperscript{42} Ibid.
\item\textsuperscript{43} CARES Act, S. 3548, 116\textsuperscript{th} Congress. (2020).
\item\textsuperscript{44} Bailey Bryant, (2020, Apr. 7). “Loopholes in the COVID-19 Unemployment Program Threaten to Deplete Home Care Workforce.” \textit{Home Health Care News}.
\end{itemize}
unemployed than by continuing to work, intensifying the demand for home care services.\textsuperscript{45} Although, the main statistic Bryant cites is for New York State, where the weekly unemployment benefit is $504; meaning that it is possible for a worker on unemployment due to COVID to earn $4,500.\textsuperscript{46} It seems unlikely other states would offer such generous compensation. On the other hand, the federal Families First Coronavirus Response Act (FFCRA) made certain essential care providers and emergency responders exempt from public health emergency leave.\textsuperscript{47} It also allowed small businesses providing these critical services to deny emergency leave to their employees.\textsuperscript{48} On the one hand, denying emergency leave to essential health care workers is a recognition of their importance, but it also places a special burden on low-wage health workers who can’t afford not to work even when their own health is being compromised.\textsuperscript{49}

**Why Direct Care Workers Ought to Be Involved in Advance Care Planning: A Practical Justification**

There are many proposals to alleviate the burdens on DCWs. Among the most obvious is to compensate them more fairly for what they do. The primary payer for direct care is typically state Medicaid programs that provide coverage for personal care under home and community based waivers.\textsuperscript{50} Medicaid has a consumer-directed option that allows enrollees to directly

\textsuperscript{45} Ibid.
\textsuperscript{46} Ibid.
\textsuperscript{47} Families First Coronavirus Act, Division C-- Emergency Family and Medical Leave Expansion Act, Sec. 3102: “With a finding of good cause, the Department of Labor may (1) exclude certain health care providers and emergency responders from eligibility for public health emergency leave, and (2) exempt employers with fewer than 50 employees if the requirements of this section would place the viability of that business at risk.” https://www.congress.gov/bill/116th-congress/house-bill/6201
\textsuperscript{48} Ibid.
\textsuperscript{50} Ibid., 330.
employ DCWs, which some find provides greater choice and autonomy for recipients.⁵¹ Yet, it is important to recall that Hansen et al’s Oregon study of care workers facing abuse focused on those who were privately employed in a consumer-based system. Shifting to a consumer-based approach to care provision may also fail to provide the support systems workers need when coping with abuse on the job. Furthermore, because Medicaid is funded through general revenue, it is often underfunded and structured in ways that make it difficult to balance the needs of recipients and workers.⁵² Medicare, the other main agency which reimburses DCWs, also provides very limited coverage for non-institutionally based personal care services.⁵³

It is unlikely the U.S. will be able to move away from a government entitlement approach to compensating DCWs for the work they do. For the most part, chronically ill and dying people are certainly unable to compensate them out of pocket. There is also not much incentive for private companies to pay them better and improve their working conditions. Some potentially viable proposals include creating career ladders that would help DCWs attain education, professional development, and career advancement.⁵⁴ Although, as Ariel Ducey points out in _Never Good Enough: Health Care Workers and the False Promise of Job Training_, health care institutions throughout New York City attempted this in the mid-90s. At that time and place, unionized health care workers were beginning to make demands for higher pay and better

---

⁵¹ Stephen Campbell et al., _Caring for the Future: The Power and Potential of America’s Direct Care Workforce_, 38.

⁵² Ibid., 33.


working conditions, and hospitals responded by threatening layoffs.\textsuperscript{55} Job training initiatives were proposed, and the unions embraced them as a way of avoiding layoffs and pay cuts.\textsuperscript{56} But, the training initiatives failed to address the problems faced by workers, and sometimes even blamed them for the systemic issues neither the hospitals nor the unions were able to address.\textsuperscript{57} In the end, proposed training programs did almost nothing to improve compensation, professional status, or job satisfaction for care workers.\textsuperscript{58}

It seems DCWs are inevitably most subject to labor exploitation, and on a personal level, most likely to be coping with the effects of racism and sexism. Health care provision in general must navigate the tension between neglect and holding on to life at the expense of engaging with patients’ personhood in decline. DCWs navigate this tension in their every interaction with their clients and patients, making constant judgment calls about when, how, and if they should intervene when their charges’ personal capacities fluctuate and decline. They are forced to consider how intervening or not intervening will affect their alliances and trust with clients on a continual basis, and they are arguably more likely than other practitioners to be impacted by economic constraints as they navigate how to provide the best possible care.

But, on a practical level, this also makes them best situated to ascertain and prioritize what can be done to enhance agency and quality of life when resources are scarce. This is a positive skill DCWs must cultivate to succeed in their work. Because DCWs spend the most time interacting with their patients or clients, it is a professional liability for DCWs not to be able to

\begin{flushright}
\textsuperscript{56} Ibid.
\textsuperscript{57} Ibid., 6.
\textsuperscript{58} Ibid., 7.
\end{flushright}
read their mannerisms and respond to their needs. If the health care system wants to avoid overtreatment as the result of a crisis response and unnecessary institutionalization, it should recognize this expertise on the part of DCWs. It should include them in devising personalized, workable, social, and relational approaches to end of life care. This move would help to counter the exploitation and devaluation to which DCWs continue to be subjected.

Although there are obstacles to effective compensation by Medicare and Medicaid for care work, compensation is somewhat more straightforward for advance care planning (ACP) services. It seems that subsidizing access to care would be an easier problem to tackle than planning for the ambiguities of end of life, but ironically this is not the case. By contrast, standards for Medicaid compensation for ACP are fairly clear. If an individual or designated surrogate wants to plan for care, the guidelines for Medicare reimbursement indicate that they should meet with a physician or other qualified health care practitioner: “Advance care planning include[es] the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate”.\(^59\) What other roles might “other qualified health care professionals” include? Non-physician practitioners comprise roles such as nurse practitioners (NPs), physician assistants (PAs), or clinical nurse specialists (CNSs).\(^60\) So, a patient or designated surrogate might also meet with an advance practice nurse or physician’s assistant to discuss and document their preferences for care.


\(^{60}\) Ibid.
Chapter four, “Historical Failures of ACP”, explored in detail the reasons why physicians and advance practice nurses are not necessarily well-suited to facilitating ACP, but the sensitivity and insight DCWs gain through their work makes them good candidates for leading discussions about end of life care preferences. Before the pandemic, both MDs and APRNs cited lack of education and lack of time as the reasons they avoided ACP conversations. Being forced into crisis standards of care by the pandemic has assuredly intensified these barriers. As noted in Chapter five with reference to the Respecting Choices Model, the practitioners ultimately best suited to facilitating advance care planning were generally already health care staff who had 30 to 90 minutes available during their work week to meet with patients. In theory, they might spend half an hour a week with the patient, and then an additional half an hour coordinating with the health care team and social services. If Medicare and Medicaid were to adjust their criteria to include DCWs who become certified in ACP, these workers could earn additional compensation and recognition for these vital services.

DCWs who wanted to become facilitators would nevertheless have to complete training and earn certification to provide ACP services. It would also be of benefit to require aspiring ACP facilitators to meet a certain number of client hours to enroll in an ACP certification program such as Respecting Choices. Thus, ACP would not be among the ordinary responsibilities attributed to DCWs in their primary professional role: they would earn separate compensation for the time they spend getting to know a patient and helping them sort through their preferences for care at end of life. Instead of an additional duty tacked on to already overstretched and underpaid workers who are not as well placed in the medical hierarchy, becoming an ACP facilitator could be a source of supplementary income and professional status for those direct caregivers who are able to take on this additional specialization.
Granted, not all DCWs would be equally able to earn certification to conduct ACP or would have the time available to do so. It might be difficult for say, a full-time CNA or PCA working in a hospital to also spend 90 minutes a week meeting with other patients and helping them discern their care preferences. These professionals typically work three 10 to 12 hour days per week, and may care for as many as eight to ten patients per shift. Becoming an ACP facilitator would be much more achievable for a part-time CNA working in a hospital or nursing home, a home health aide, or a long term caregiver. In fact, becoming an ACP facilitator might be an ideal second job for aging home health aide who may find more than two long shifts a week too physically demanding. Such a worker would have the expertise and sensitivity to help patients with their activities of daily living, and could use this perspective and insight to help other patients who are not directly in their care set limits for what care they want at end of life.

One might still object that DCWs are just as in demand and overworked as doctors and nurses, and would equally not want responsibility for conducting ACP. It is certainly true that not all nursing staff would have hours during the week they could devote to learning and conducting ACP. However, among roles of healthcare provider, the professional obligation of direct caregivers is most oriented toward getting to know a patient personally, prioritizing the ethical value of providing sensitive and compassionate care to patients navigating decline. In comparison to physicians, who are primarily charged with diagnosis and prescription, and nurses, who administer medications and treatments, nurse assistants are most responsible for helping patients with the activities of daily living. This involves a level of sensitivity, interpersonal awareness, and judgment not always expected of these other practitioners.

DCWs are most charged with ensuring the patient gets through their day: they assist patients with eating, resting, exercising, using the bathroom and offering social support. This is
far from being the “unskilled” labor by which it is typically known, and requires sensitivity to
more than just the patient’s physical needs. As Jennifer Parks points out in *No Place Like Home?*, understanding direct care work as simply “washing bodies and feeding mouths”
minimizes the breadth of care work, and may very well be “devastating to those aides who
understand themselves in a more relational sense, as helping to make clients feel as much as
possible like whole persons, and treating them accordingly.”61 Direct caregivers are most
professionally obligated to support the needs of the ill, elderly and disabled people who enter the
healthcare system and thus have a right to their help. When DCWs take on the role of ACP
facilitators, they are most likely to have the skill needed to discern the character and preferences
of the person they care for as a result of their experience helping others with the intimate
necessities of life.

In *Being Mortal*, Atul Gawande describes the experience of the palliative care specialist
at his hospital and her dying father, and it is a good illustration of why the kinds of
considerations that matter for successful caregiving are the same considerations that matter for
good quality advance care planning. The specialist Susan Block’s father was a 74 year-old
professor emeritus of psychology at UC Berkeley, who was suffering from a mass growing in the
spinal cord in his neck.62 She and her father met with their neurosurgeon, who explained that the
procedure to remove the tumor carried a 20% chance of rendering him quadriplegic, while
without the surgery he faced a 100% chance of becoming paralyzed from the neck down.63 For

61 Parks, Jennifer A. *No Place Like Home?: Feminist Ethics and Home Health Care*, 69.
63 Ibid.
most doctors, this is the key to medical decision making: determining the risks and benefits of treatment, and figuring out which treatments people want. But Block says that this is the wrong approach for caring for the aging and chronically ill. Instead, we ought to focus on what is most important to that person under the circumstances, and what would make their lives tolerable or intolerable.\footnote{Ibid., 182.}

At first Block avoided asking her father these questions, but finally sat down with him and told him that she needed “to understand how much you’re willing to go through to have a shot at being alive and what level of being alive is tolerable to you.”\footnote{Ibid., 183.} His answer surprised her. Although most of his life was devoted to teaching psychology and working as an academic, he told Dr. Block that he would be willing to stay alive so long as he could eat chocolate ice cream and watch football on TV.\footnote{Ibid.} After consenting to the procedure, he experienced bleeding in his neck while in recovery. Without this discussion, Dr. Block said that “her instinct would have been to let him go” rather than send him through another procedure that would be unlikely to improve his prognosis much.\footnote{Ibid.} He ended up experiencing a painful recovery and long term disability, but managed to publish two books and more than a dozen scholarly articles in the years he had left, and was glad his daughter made the decision that she did.\footnote{Ibid.}

Dr. Block’s father is perhaps a more unlikely example than Edmund’s alternate ending in Chapter five, or Françoise de Beauvoir in Chapter six, but he bears inclusion on the grounds that
sometime a calculated risk in favor of treatment is a valid choice. However, I maintain that the
determining ground for the validity of these choices goes back to a person’s relational network
and how much they think they will be able to tolerate pain, suffering, and disorientation as they
face decline. It is important that they have support not just from their immediate relational
network, but institutional support in communicating their choices to the relevant providers.
Again, I find the skills of DCWs would help them ask the right questions, as Dr. Block did for
her father.

Direct caregivers are typically in the position of having to determine what is most
important to the person they care for, and what activities would make their lives tolerable or
intolerable. A care aide who spent their time with their patient discussing medications,
treatments, risks, and benefits would likely be a less successful caregiver than someone who
helped their patient meet their needs such that they could get outdoors, read, listen to music,
watch their favorite program, or even play a game. While providing diagnostic information is
important, so is helping someone live as well as possible in the face of chronic illness and
decline. Ultimately, one would hope these two processes would complement one another in ways
which help patients gather information, deliberate with loved ones, and also make time to do
what is most meaningful to them. To succeed in their work, direct caregivers must develop
sensitivity to context, the ability to consider their patients’ values, and the capacity to manage
their patients’ needs. This amounts to a particular skill set more likely to be honed by direct
nursing care workers than any other health care profession.

However, there are legal barriers to a direct caregiver serving as their patient’s advance
care planner. Someone who is actively caring for the patient or resident cannot also conduct ACP
with them because it would be a conflict of interest. And, as noted previously, the caregivers
who are most available at the bedside and who spend the most time with the patients would still face barriers to finding time and earning appropriate compensation to conduct ACP with their patients. Not all nursing staff are equally able to take on additional work as advance care planners: full time hospital CNAs would be less able to become ACP facilitators than part time CNAs, for example. However, the skill set developed by direct caregivers is, as I argued in the previous paragraph, similar to the skill set needed for quality advance care planning. Care planners need to be able to focus on what gives their patients a good quality of life, and help them think through how they might achieve it. So, even though a DCW who becomes an ACP facilitator cannot directly rely on their own experience caring for specific patients to help these same people plan care at end of life, they would still have a particular professional attunement and insight into the kinds of considerations that matter for ACP. They might be more likely to inquire about what kinds of activities make life worthwhile rather than segueing to a potentially less relevant consideration of the risks and benefits of particular treatments supposing they had knowledge of them.

Why Direct Care Workers Ought to Be Involved in Advance Care Planning: A Moral Justification

Section one of this Chapter discussed the myriad impediments DCWs face to adequate respect and compensation for what they do, while section two offered a practical justification for how becoming ACP facilitators could mitigate this harm. This section considers the possibility that DCWs may also feel their worth and find job satisfaction when they enter into what Tracy Karner describes as “fictive kin” relationships. I agree with Karner that these relationships are morally salient, but I do not find that achieving fictive kin relationships could serve as a guiding ideal for care provision. While these relationships are valuable when they do happen, good care
provision also entails accepting that one will not relate to every client in this more intimate way. Thus, while some care workers may find recognition and satisfaction when they have these relationships, more is due to them from society as a whole.

This Chapter will close with an explanation of Eva Kittay’s theory of connection based equality. This approach proposes we ought to understand dependency relationships as “nested” throughout interpersonal experience, with greater social responsibility for protecting the wellbeing of those providing care. In the end, I claim that employing DCWs as ACP facilitators would allow them to contribute to the morally valuable relational work involved in holding loved ones through the dying process. Facilitating ACP would help DCWs earn more and potentially improve their standing in the system, while relational networks coping with the decline of a loved one could benefit from their support. This approach would enhance the agency of these interdependent, nested parties, I argue.

Among phenomena that bring job satisfaction to DCWs and imbue their work with meaning is that of becoming “fictive kin” with their clients: a concept introduced by Tracy X. Karner in the article “Professional Caring: Homecare Workers as Fictive Kin”. Although American society still holds on to the myth than one’s descendants will one day provide all-encompassing care for them in decline, the reality is that most older people will require some kind of formal assistance by paid caregivers. This myth depended on the often exploitative socialization of women within the family to provide care, and the reinforcement of this positive

---


skill by the community at large. Much as caregiving is a positive skill, the socioeconomic reality is that most women need to work outside the home; whereas men in general are still not trained or expected to do housework well or provide good quality child or elder care routinely. Furthermore, many older people live below the poverty line and need help from their families or communities going through activities of daily living. With the reality that most family members cannot abandon their livelihood to provide care, it is beneficial that paid caregivers can step into a family-like relationship through mutual engagement in intimate tasks in the home. By doing so, they can be adopted as “fictive kin”: allowing the elder to maintain an important sense that they will be cared for, and potentially providing the care worker with a positive sense of meaning in her work.

There are three stages to the development of a fictive kin relationship: the task oriented introductory phase, the sharing of selves in a friendship stage, and the familial adoption. In the introductory stage, the caregiver and their client meet as strangers and begin cooperating to perform specific tasks of home and personal care. On one caregiver’s analysis, this involves asking their client questions such as “Can I, may I, is it alright if I do this?” and attending closely to their client’s responses. Carrying this out in a respectful way establishes norms for how care

---

71 Ibid., 70.
72 Ibid., 72.
73 Ibid.
74 Ibid., 75.
75 Ibid.
76 Ibid.
will proceed, and how the caregiver will negotiate issues of privacy and dignity.\textsuperscript{77} Even experienced caregivers cannot anticipate all the nuances of care provision without engaging in this kind of interaction, and the details of the roles taken on by the care provider and recipient are often new for both parties.\textsuperscript{78} However, it seems plausible that a good caregiver would be better able to anticipate what kinds of considerations will be important in maintaining privacy, dignity, and ultimately quality of life for their client.

If communication proceeds well and trust is built in the introductory phase, it is possible that the care worker and their client can begin to share more intimate details about their selves and lives. The “sharing of selves phase” deepens the relationship to a level of friendship where both parties feel they are gaining something beyond the specific employment exchange of tasks and paychecks.\textsuperscript{79} There is a strong connection between sharing intimate spaces and exchanging confidences, Karner claims.\textsuperscript{80}

I find Karner’s assertions about alliance building plausible for the most part, but it is worth considering some of the interpersonal conflicts that could compromise such alliances. Because so many older people who can arrange to have paid caregivers are white and many care workers are immigrants and people of color, opportunities for older people to make ignorant or demeaning comments are rife even if they have good intentions. While there is no ready-made analogy between gender and race-based oppression, it is also a fair generalization that many elders would be intolerant of LGBTQ+ caregivers and perhaps completely taken aback by an out

\textsuperscript{77} Ibid.

\textsuperscript{78} Ibid.

\textsuperscript{79} Ibid., 76.

\textsuperscript{80} Ibid.
trans care provider. And, of course, there is the more commonplace problem that many men who came of age mid-century continue to hold on to sexist and demeaning expectations of women. So, while I accept that it is morally valuable when caregivers and their charges manage to achieve a fictive kin relationship, I would argue this is not necessarily needed for good care provision.

Furthermore, if a care worker moved into friendship-like sharing without establishing trust and norms around the forms of care they will provide, this stands to be inauthentic and potentially manipulative. An unscrupulous caregiver could maintain superficial friendship-like relations with their client: failing to actually attend to their needs, but giving them the impression they are cared for. Many older people are lonely, and might settle for companionship even if their caregiver isn’t actively collaborating with them in satisfying personal or household needs. Karner notes that while care workers found meaning and job satisfaction developing friendships with their clients, supervisors often discouraged this kind of interaction. Moving into a more friendship-like collaboration with one’s clients can open the door to exploitation on both sides. But, I would agree with Karner that to the extent that when the more basic relationship of caregiving unfolds in ways that are fair to both parties, it is morally valuable to engage in a mutual sharing of selves in care work.

The morally salient possibility of being able to support a client in a fictive kin relationship can confer a degree of job satisfaction in some cases, but it is ultimately not enough to ground what society as a whole owes to DCWs. It is unjust to ask DCWs to cope with poverty and exploitation for the far off possibility that they may perhaps find satisfaction in supporting a

---

81 Ibid., 77.
client in this way. As Eva Kittay argues in Love’s Labor: Essay on Women, Equality and Dependency, it is insufficient to consider only the vulnerability of the care recipient in connection to the vulnerability of the care worker. Instead, “…the circle of dependency obligations must expand to include the vulnerability of the dependency worker, which is itself a consequence of her deferred interests as well as needs pertaining to her affective bond to her charge and her concern for her charge’s well-being.” DCWs are not necessarily in a voluntaristic position with respect to their labor, and their vulnerability matters along with the vulnerability of the care recipient. Thus, we ought to move beyond an individually-based conception of equality to a connection-based conception of equality.

Rather than a version of equality which begins with a notion of persons as separate, discrete individuals, it would be preferable to acknowledge that each person is nested in relationships of care. This notion of Kittay’s aligns with my claims about agency in Chapter two: people achieve agency by forming supportive alliances in lived socio-political context. The care extended to someone (or not extended to them) in a family of origin impacts the friendships and alliances they might find in a community of choice, and thus the kinds of counterstories needed to restore their agency. Kittay’s connection based equality assumes a fundamental need for relationship, and certain corresponding entitlements to care from specific others as well as society as a whole.

---

82 Kittay, Eva. Love’s Labor: Essays on Women, Equality and Dependency, 70.

83 Ibid., 71.

84 Ibid.

85 Ibid.

86 Ibid.
More specifically, connection based equality takes relationships as legitimating grounds for two key claims. The legitimacy of these claims does not depend on what rights we hold as independent individuals; claims are legitimate or not on the basis of what is owed to us on the basis of our connection to those with whom we have had or are likely to have relationships of care and dependency. In other words, the relationships we have in the sense of being a mother’s child, a best friend, or a supportive partner, are the determining ground for what is owed to us as persons. Thus, Kittay’s first claim is that we are entitled to relationships in which one can be cared for when appropriate. Her subsequent claim is that we are all entitled to a socially-supported situation in which one can give care without the care-giving becoming a liability to one’s own well-being. The latter is the key point for DCWs or dependency workers, and it is one we have yet to achieve.

Kittay offers family leave policies as one way of attending to the second claim, and I argue that balancing care work with ACP facilitation is another way to ensure these claims are met. ACP facilitation allows DCWs to repurpose the relational skills they have already honed in ways which contribute to the morally significant capacity we have to hold loved ones through the dying process. Kittay adds that the larger social order ought to foster the preservation and flourishing of dependency relations in a manner that avoids creating the debilitating secondary dependencies so detrimental to women today.

---

87 Ibid.
88 Ibid.
89 Ibid., 71-2.
90 Ibid., 72.
91 Ibid., 75.
I find that engaging care workers as care planners would empower them in ways which would foster healthier, more agency-preserving dependency relationships. This approach would give them additional financial compensation, better allowing them to meet their own socioeconomic needs. ACP is also less physically demanding than direct care work, alleviating some of the bodily strain placed on DCWs. Their service in the care planning process would help more aging and chronically ill people navigate the health care system, and enhance the possibility that they will achieve an appropriate death. If it is possible for dependency relationships to flourish, it is important to change the health care system in ways that give adequate respect to the agency and contributions of care workers, supporting them in their own navigation of dependency networks.

**Conclusion**

As I noted in the concluding paragraphs of section one of this Chapter, DCWs receive some of the lowest wages of all health care providers, are more likely to have to work multiple jobs, and are more likely to have to rely on public assistance to meet their own needs. They were not included in the Fair Labor Standards Act until 1974, and the so-called “companionship exemption” still renders them ineligible for key provisions such as a minimum wage, overtime, or paid time off.92 The legacy of Jim Crow detracts from the worth society ought to have for their work, if it garners social recognition at all. Care work traditionally performed by women is devalued and rendered invisible by a society that would prefer to pretend no one needs care to achieve agency. The structural disarray of the home care industry will continue to complicate the lack of recognition and under compensation of DCWs, while their employers’ ability to protect

---

them from abuse is still largely insufficient. These are all deeply rooted problems that will not be immediately remedied by simply training and certifying DCWs to practice ACP.

However, because they are constantly coping with the boundary between overtreatment and neglect in intimate interactions with their clients, DCWs have valuable insight that could position them to be good allies to chronically ill and dying people. This is of both practical and moral significance. Care workers and chronically ill and dying people are interdependent, and it would contribute to their mutual agency to give more power to DCWs to help people think through and formalize their alliances and end of life care goals. Care workers would advance professionally, earn additional money, and be engaged in a less physically demanding type of work. People who want to plan for end of life would benefit from the perspective of care providers who know what it takes to achieve meaningful quality of life when one’s capacities are diminishing. Families and relational caring networks would also benefit from having someone who knows the health care system connect them with local services and ensure their ADs are situated where other care providers can access them.

Such an approach would build up the ‘nests’ of nested dependency, and help to reattribute worth to work so often devalued for gendered and racist reasons. Much as we cannot take it for granted that a community is comprised of collaborative relationships, allowing care workers to serve as care planners would empower them to collaborate with people who want to plan for their decline—which most everyone should. Most everyone would prefer to die an appropriate death, thus, we all have an interest in recognizing and supporting caring workers who can help us achieve it.
CONCLUSION

How the health care system will recover from the COVID-19 pandemic remains an open question, but at least one lesson is clear: we need to rethink standards for care for those coping with aging and decline. Failing to do this will subject more people to unenviable dying processes, especially when another health crisis emerges. I have argued throughout this project that we could accomplish this is by empowering DCWs to serve as ACP facilitators, a move that recognizes the value of their professional insights and which could potentially help them out of poverty. This approach would reconfigure the relational network of care providers and their charges in ways that rebuild the compromised agency of both parties. Unlike technological proposals to broaden ventilator access, for example, expanding access to ACP would prompt people to consider if these interventions are even desirable, and help them set boundaries for the kinds of care they find appropriate.

As much as it seems like common sense to factor in ACP as one among many forms of social cooperation, it is important not to take for granted that communities are collaborating in functional ways, as I argue in Chapter two. Especially groups like older, chronically ill people, and the undercompensated, underrecognized workers who care for them need alliances that will support their agency and counteract social narratives that demean them and deprive them of a voice. Meanwhile, as I argue in Chapter three, as much as we might want to revalorize the more immediate cares of people coping with dementia and decline, they are also owed active support for their agency. Those who care for them should help them ascertain what is in their interest and persuade them toward it. It is not necessarily the responsibility of public health agencies or
medical teams to engage directly with them; in an ideal situation, a partner or close friend should “hold” them in their identity and help them deliberate about what practices or treatments are worthwhile. I grant that trust must be placed with various health care providers, but the capacity of these providers to recognize some of the less scrupulous maneuvering of drug companies and insurance providers is trust-building in and of itself.

Failures of communication are at the root of the historical failure of ACP, but recognizing persistent barriers and attributing responsibility to specific health care providers would help counteract these failures. The promise of the care planning process is too great to abandon, as the results from the Respecting Choices program at Gundersen Health System demonstrate. With few exceptions, most people would prefer to die what Weisman and Hackett conceive of as an appropriate death, and it is well within the purview of responsibility of the health care system to help people achieve it. It could also meet this responsibility in ways that counter the historical devaluation of care work along sexist and racist lines. Given that it was not until the seventies that nursing care providers working in private homes could advocate for a minimum wage or overtime, government agencies ought to support the health care system’s responsibility to those who provide its most basic service of direct care.

I hope my research throughout this project has challenged unproductive idealizations about the health care system, care workers, and end of life care. Whether the health care system errs on the side of overtreatment or neglect, it is important to conceive of realistic ways of avoiding these pitfalls. Recognizing the role-related institutional pressure on doctors to save lives is still important, as I argued in Chapter five, but it would be helpful to train and compensate care planners who can help their clients navigate uniquely personal boundaries about the value of cure.
and care in end of life. Perhaps my arguments in favor of such a process could lead to the
development of a training program, or contribute to an extant one.

Although this speculation goes beyond the dissertation as it stands, I suspect that care
workers such as myself would be motivated to help others set boundaries about their end of life
care, and formalize the relationships that would lead to a more manageable decline. Aside from
potential exploitation and abuse on the job, many direct care workers experience moral distress
or feelings of powerlessness helping their charges through the dying process. Although it would
be a conflict of interest for them to plan care for someone they are actively caring for, it might be
valuable to their own self-respect and agency to help other patients through ACP. It may also
alleviate some of the strain family caregivers experience as they collaborate with other health
care providers. If we accept Kittay’s suggestion that society is comprised of various nested
dependencies, it would be advantageous to find and bolster relationships of active collaboration
rather than assume they exist within any institution or group.

Once again, it is possible to do this in ways that reattribute respect to direct care workers,
giving them the requisite training and compensation to engage in a process so often avoided, but
which is perhaps most responsible for the achievement of an appropriate death. The COVID-19
pandemic has already demonstrated the insufficiency of our current, avoidant response to end of
life care planning. I believe the approach I defend herein is a viable alternative, one that would
empower those who stand to suffer the most from another global health crisis. I hope to pursue
further research in bioethics and program development which meaningfully challenge forms of
social injustice, and which in turn prevent each person from living, working, and dying well.
BIBLIOGRAPHY


Campbell, Stephen et al., Caring for the Future: The Power and Potential of America’s Direct Care Workforce, PHI (2020), http://phinational.org/caringforthefuture/


Families First Coronavirus Act, Division C-- Emergency Family and Medical Leave Expansion Act, Sec. 3102, 116th Congress, (2020).


Lindemann, Hilde. *Damaged Identities, Narrative Repair*.

Lindemann, Hilde. *Holding and Letting Go: The Social Practice of Personal Identities*.


Parks, Jennifer. *No Place Like Home?: Feminist Ethics and Home Health Care*.


206


VITA

Ciaran Folliard Rhys earned a B.A. in Philosophy and Art/Art History from Kalamazoo College, while working nights as a patient safety sitter. As a patient care associate with nursing union representation in the interim, Rhys earned an M.A. in Philosophy with a focus on Feminist and Gender Studies from the New School for Social Research. During their time as a PhD student in Philosophy at Loyola University Chicago, Dr. Rhys has balanced an inspiration for teaching philosophical and applied ethics with a consideration for the structure and relational functioning of health care institutions as they operate in practice.
DISSESTATION APPROVAL SHEET

The dissertation submitted by Ciaran Folliard Rhys has been read and approved by the following committee:

Jennifer A. Parks, Ph.D., Director
Professor of Philosophy
Loyola University Chicago

Mark H. Waymack, Ph.D.
Professor of Philosophy
Loyola University Chicago

Joseph M. Vukov, Ph.D.
Professor of Philosophy
Loyola University Chicago

The final copies have been examined by the director of the dissertation and the signature that appears below verifies the fact that any necessary changes have been incorporated, and that the dissertation is now given final approval by the committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

__________________  ____________________
Date                      Director’s Signature