OUR BODIES, OUR LIVES, OUR RIGHT TO DECIDE?

REPRODUCTIVE FREEDOM, SELF-DIRECTED DYING,

AND WOMEN'S AUTONOMY

by

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

of

Doctor of Philosophy

in

American Studies

MONTANA STATE UNIVERSITY
Bozeman, Montana

November 2017

ACKNOWLEDGEMENTS

First, I thank the ten veteran reproductive freedom activists whose names, backgrounds, and insights are featured in the final chapter of this dissertation. They trusted me to keep specific confidences and to reflect their views with integrity. This study would not have been possible without their insights. Second, I thank the five members of my dissertation committee: Dr. Mary Murphy (History); Dr. Robert Rydell (History and American Studies); Dr. Kristen Intemann (Philosophy); Dr. Walter Fleming (Native American Studies); and Dr. Elizabeth Rink (Health and Human Development). Between them, they provided valuable guidance, excellent editing advice, and superb examples of accessible writing on a range of academic subjects. Third, I thank the abortion rights pioneers with whom I collected oral histories three decades ago, especially Laura Kaplan. I did not thank Laura publicly when I published my Master's thesis under the name *Abortion without Apology;* my information about the Jane Abortion Service came from her, but many former Jane members were still not using their own names because their actions had been illegal. Since then, Laura has published the history of Jane. I now have the opportunity to thank her for introducing me to the radical history of the abortion rights movement years ago*,* and also for later introducing me to the National Women's Health Network, where I learned about the reproductive justice model that informs this work. Finally, I thank my mother, Cj Baehr, who helped edit this document, and my wife, Lori Hiris, who provided moral and financial support so that I could focus on completing this project.

TABLE OF CONTENTS

1. INTRODUCTION 1

Positionality Statement 1
Overview 5
Background 6
Relevance 9
Gender-Based Caregiving Disparities 10
Gender-Based Financial Disparities 11
Gender-Based Life Expectancy Disparities 11
Framework 16
Autonomy 24

2. AUTONOMY IN FEMININE AND FEMINIST ETHICS AND SELF-DIRECTED DYING 30

Autonomy in Feminine and Feminist Ethics 30
Feminine and Feminist Ethics and Self-Directed Dying 34
Autonomy and Self-Directed Dying 44

3. PARALLELS BETWEEN THE ABORTION MOVEMENT OF THE 1960s AND 1970s AND THE RIGHT-TO-DIE MOVEMENT TODAY 87

Referrals, Travel, and “How To” Handbooks 88
Referrals 88
Travel 97
“How To” Handbooks 100
Self-Help Groups 106
Self-Examination and Menstrual Extraction 106
Jane 111
Medicalization, Therapeutic Committees, and Reform v. Repeal 119
Medicalization 119
Therapeutic Committees 122
Reform v. Repeal 124
Reproductive Justice 131
Population Control 132
Single-Issue Organizing and Meaningful Choice 147
Inclusive Organizing 148

TABLE OF CONTENTS CONTINUED

4. VETERAN REPRODUCTIVE FREEDOM LEADERS' VIEWS ON SELF-DIRECTED DYING 162

Interviewees 162
Five Themes Relevant to How Highlighting the Parallels between the Struggle for Abortion and the Struggle for Self-Directed Dying Might, or Might Not, Draw Support from Baby Boomer Veterans of the Reproductive Rights Movement for the Right-to-Die Movement 174
Two Lessons Learned from the Reproductive Justice Movement 184
Three Additional Considerations 188
Synthesis 198
Observation: Movement Similarities, Issue Differences 199
Conclusions 214
Reflection 221

BIBLIOGRAPHY 227

APPENDICES 247

APPENDIX A: Pre-Interview Information and Questions Provided to Women Interviewed 248
APPENDIX B: Suicide Statistics in the U.S. 253
APPENDIX C: Health Behavior Change: Women and End-of-Life Care 266

LIST OF FIGURES

Figure Page

1. Population Aged 85 and Over, 1900 to 2050 10
2. Differences between Male and Female Populations by Age, 2010 12
3. Population by Age and Sex, 1970 13
4. Population by Age and Sex, 2010 13
5. Population by Age and Sex, 2030 14
6. Population by Age and Sex, 2050 14
7. News Magazine Talks about Do-It-Yourself Abortion with Maginnis 90
8. Irreversible Illness? Unbearable Suffering? Die with Dignity 96
9. A Private Matter 98
10. A Terminal Cancer Patient's Controversial Choice 99
11. Del-Em 109
12. Co Gen 110
13. Do It Yourself with Betty 111
14. Jane: Celebrate People's History 112
15. God the Mother Message – Therapeutic Abortion 123
16. God the Mother Message – Reform/Repeal 125
17. Stop Forced Sterilization 146

GLOSSARY

Abortion Rights Movement: A political movement begun in the early 1960s to promote women's access to legal abortion.

Assisting Suicide: Taking action to assist another person in bringing about his or her own death. Assisting suicide is illegal throughout the U.S. except in cases of legal physician-assisted suicide, also called "physician aid in dying" or "medical aid in dying." (See below.)

Civil Rights: Generally understood to mean legal rights accorded to some or all individuals within a country, territory, or other entity according to that entity's constitution or other legal documents; for example, the right to privacy legally accorded to citizens of the U.S.

Euthanasia: The administration by a physician of medication for the purpose of ending a patient's life. Euthanasia is not legal anywhere in the U.S. but is legal in some European countries.

Hastening One's Own Death: A term sometimes used to imply that terminally ill people who commit suicide are hastening an inevitable and imminent death; technically, as everyone will die, any person who commits suicide is hastening his or her own death.

Human Rights: Moral principles generally understood to mean conditions or protections due to people simply because they are human, including negative rights, such as the rights to be free from slavery and torture, and positive rights, such as the rights to access basic necessities including food, shelter, education, health care, and more.

Irrational/Impulsive Suicide: The concept that for some people, in some circumstances, taking action to cause their own death might be resorted to without due consideration because of mental illness, intoxication, stress, or other conditions that render the person unable to fully and realistically consider his or her options and make choices in his or her own best interest.

Medical Aid In Dying: A term used recently by mainstream U.S. right-to-die advocates to replace "physician aid in dying." (See below.)

GLOSSARY CONTINUED

Physician Aid In Dying: The practice of a physician prescribing a lethal dose of medication to a patient. Physician aid in dying is legal under strictly regulated circumstances in Oregon, Washington, Vermont, California, and Colorado and is also permissible in Montana. The medication must be taken by the patient, not administered by a physician or anyone else. “Physician aid in dying” is preferred by mainstream right-to-die advocates over the term “physician-assisted suicide,” below, for at least three reasons: 1) the public has a very negative view of “suicide,” 2) the official cause of death of U.S. patients who utilize physician aid in dying is listed as the underlying terminal illness and not as suicide; and 3) advocates claim that in cases of terminal illness, the only cases in which aid in dying is legal in the U.S., the patients involved are not people who want to die; rather, they are people who want to live but who, unfortunately, are dying of a terminal illness.

Physician-Assisted Suicide: Same as “physician aid in dying,” Mainstream right-to-die advocates reject the term “physician-assisted suicide,” arguing that to say terminally ill patients receiving such aid are committing suicide is inaccurate and that it is offensive to many such patients and those who survive them, as the patient is dying of an underlying terminal illness. While this distinction may be valid in the U.S., where only people predicted to die of a terminal illness within six months may receive aid legally, it is less valid in countries where physician assistance in hastening death is not limited to the terminally ill but may also be available to the non-terminally ill.

Pro-Abortion Movement: A movement in the 1960s and early 1970s to make abortions--legal and also illegal--more available to women.

Pro-Choice Movement: A post-*Roe v. Wade* rebranding of the abortion rights movement, named to refer to “choice” rather than to use the word “abortion,” which carried a stigma; the term is currently falling out of favor among organizations supporting women’s access to abortion.

Rational Suicide: The concept that for some people, under some circumstances, taking action to cause their own death might be seen as a rational option.

GLOSSARY CONTINUED

Reproductive Freedom Movement: A political and social agenda including, but not limited to, women's access to abortion; other social and economic issues, such as women's ability to express themselves sexually, to be free from sexual violence, to have access to a range of contraception options, to conceive and deliver children as they see fit, and to have access to child care and to other social and economic conditions supporting their child rearing are considered important.

Reproductive Justice Movement: A movement formed and led by women of color supportive of the reproductive freedom agenda who take not only civil rights but also human rights into account; various compatible reproductive justice agendas have been put forth by various groups of women based on their particular experiences regarding reproduction.

Self-Directed Dying: A term borrowed from Dr. Margaret Pabst Battin, who describes our society's current view of death as *something that happens to you* (perhaps even something to be prevented or at least delayed at virtually any cost) rather than *something you do* – a deliberate, planned activity, one's final and culminating activity.[1] "Self-directed dying" may, but does not necessarily, include suicide, assisted or otherwise.

Suicide: The act of intentionally bringing about one's own death. Suicide is not a crime in any state, but it is generally considered something to be prevented; the word "suicide" carries a stigma.

[1] Margaret Pabst Battin, "Physician-Assisted Suicide: Safe, Legal, Rare?" in *Physician-Assisted Suicide: Expanding the Debate,* ed. Margaret Battin, Rhodes, Rosamond, and Silvers, Anita (New York: Routledge, 1998).

ABSTRACT

Statement of Problem: Autonomy is a key and evolving concept in American identity. As the bioethical concept of patient autonomy develops and the elderly population in the U.S. grows, end-of-life decisions including self-directed dying are increasingly a matter of public debate. This study explores how veterans of the reproductive freedom movement view, and might be inclined to shape, the right-to-die movement. Methods: Similarities between the abortion movement in the 1960s and early 1970s and the right-to-die movement today were very briefly described to ten women who then participated in oral history interviews. Interviewees were 1) of childbearing age before *Roe v. Wade,* and 2) supportive of women's access to abortion. Women were asked open-ended questions about their own life experiences and their thoughts about self-directed dying. Results: Interviewees described their experiences with the deaths of loved ones, their personal and professional interactions with the health care system, and their opinions about self-directed dying. Conclusions: Women's personal and cultural backgrounds influenced their understanding of autonomy and the role it can, or should, play in individuals' lives. Commitment to women's self-determination was a shared core value for reproductive freedom veterans that informed their thinking about self-directed dying, but they expressed more concerns about the limitations and potential dangers of personal autonomy in relation to decisions about assisted dying than in relation to decisions about abortion. If engaged more fully, such women might emerge as a force not only to support but also to shape the right-to-die movement. Women who consider assisted dying to be a priority issue may be likely to support somewhat expanding the conditions under which individuals can receive aid in dying. Whether or not they regard assisted dying as important or even desirable, however, women interviewed regard related end-of-life issues, such as advance directives and support for care givers, as important concerns. Taken together, interviewees' input suggests that an inclusive right-to-die movement might place the specific issue of assisted dying in the context of a wider end-of-life movement addressing medical and social justice concerns that could increase the ability of all to live and die as they see fit.

PREFACE

Like abortion, aid in dying is controversial. Activists in the reproductive freedom movement have learned lessons and developed perspectives that might inform the right-to-die debate. In the following pages I reprint excerpts from oral histories that I collected in the 1980s with pioneering reproductive freedom activists, and I include excerpts from new interviews that I collected with veteran reproductive freedom activists in 2016 and 2017. Many of the earlier interviews included in Chapter 1 were first published in a pamphlet entitled *Abortion without Apology: A Radical History for the 1990s.*[2] Excerpts from the more recent interviews are presented here for the first time. My hope is that this information will prompt readers to consider, or perhaps to reconsider, self-directed dying, and to think about whether and how to include issues related to self-directed dying in their future activism. Within the Montana State University American Studies program I have selected history—specifically, women's history—as my major area of concentration, and ethics and health as my minor areas. This dissertation draws heavily on the history of the U.S women's movement for reproductive freedom but also incorporates insights from the fields of ethics, especially feminist ethics, and health, especially public health.

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[2] Ninia Baehr, *Abortion without Apology: A Radical History for the 1990s* (Boston: South End Press, 1990).

CHAPTER ONE

INTRODUCTION

Self-directed dying and reproductive freedom both raise issues of bodily integrity, social justice, medical ethics, and, especially, autonomy. As this chapter explains, the importance of autonomy as an American value was implicit in the founding of the United States. The questions of who has the right to autonomy, and what conditions are necessary to support autonomy, have been evolving ever since. This dissertation uses the history of the U.S. abortion movement and the emergence of the U.S. right-to-die movement to explore veteran U.S. women reproductive freedom activists' thoughts about the need for, and the dangers and limitations of, personal autonomy in self-directed dying.

Positionality Statement

The similarities between abortion and the right to die first became evident to me in 2010 when I was working as an organizer for the American Civil Liberties Union (ACLU) of Montana. That year, as in many others, the organization was opposing state legislative restrictions on access to abortion. At the same time, it was considering how to protect and perhaps improve the recently-won right to physician aid in dying. The Montana Supreme Court had decriminalized physician aid in dying for mentally competent, terminally ill adults, making Montana the third state to allow medical aid in dying and the first to do so

by judicial decision. Unlike Oregon and Washington, where detailed laws governed the procedures by which physicians could evaluate and might potentially aid patients seeking to hasten their own death, Montana law included few implementation guidelines. Many hoped that the Montana legislature would clarify guidelines during its upcoming session.

In preparation for the 2011 legislative session, ACLU staff held a planning meeting. Among many other issues, we discussed abortion access and affirmed the organization's opposition to restrictions such as mandatory waiting periods. When the agenda turned to the issue of physician aid in dying, most of us began by assuming that greater clarity about the regulations would benefit physicians and patients. As we talked through the many stipulations in effect in Oregon and Washington (described below), however, we realized that these procedures—especially waiting periods and the need for approval from two or more physicians—might not work well for patients in rural communities in thinly populated Eastern Montana. At one point someone said, "Why would we even want so many restrictions on this form of bodily autonomy when we would never support them when it comes to abortion?"

Although I had been an advocate of reproductive freedom and also of self-directed dying for many years, and understood that they both had to do with bodily autonomy, I had not appreciated the public policy parallels so clearly until that meeting. While many people seemed to see the two issues as different, I began to see more and more similarities. The similarities included, among other

things: the practical matters faced by individuals when a medical procedure they desired (abortion or aid in dying) was not legally available; the strategies employed by those seeking to provide or legalize abortion or aid in dying; and concerns about equity and vulnerability in a society rife with racial, social, and economic inequality.

These similarities existed, but I had not seen them until my “Aha!” moment in the ACLU staff meeting. Indeed, they would be difficult to see unless one had specific knowledge about both the reproductive freedom and right-to-die movements. Because I had a strong background advocating for women’s reproductive rights, had interviewed pioneers of the abortion movement of the 1960s and early 1970s, and was active in the contemporary right-to-die movement, I had a good vantage point from which to identify connections. Once I had this insight, I began to view the right-to-die movement through a lens informed by the feminist demand for women’s right to control our own bodies. Through this radical lens, the current right-to-die movement appeared to me to be limited and limiting, because, as explained below, it did not insist that each of us has a fundamental right to control our own body, up to and including hastening our own death. I began to envision a broader, bolder right-to-die movement.

As a veteran social change activist with experience framing issues in ways that could reach, persuade, and even motivate specific audiences, and as a strong supporter of self-directed dying, I wondered whether framing the issue of

self-directed dying in terms of similarities to abortion might reach, persuade, and motivate veteran reproductive freedom activists to support the right-to-die, and perhaps even cause them to push the movement toward bolder goals. This was my position at the beginning of my research. Had that turned out to be the case, I might have passed the conclusions of my "messaging" research on to existing right-to-die organizations so that they could craft effective messages to increase active support for the right to die from senior pro-choice women. In fact, what I discovered was that while the women I interviewed did agree that there were parallels between the movements, they did not necessarily see the issues as the same.

This project makes a significant contribution to the right-to-die movement because it documents the ways in which diverse veteran reproductive freedom activists do (and do not) view similarities between reproductive freedom and self-directed dying as meaningful. It also sheds light on their substantive thoughts, questions, concerns, and desires regarding self-directed dying, all of which are informed by their varied reproductive rights backgrounds and their varied personal experiences. It is important to point out the connections between the issues, in part because, as the interviews demonstrate, at least some women respond to these connections by seeing self-directed dying in a new way, as I did. It is also important to take into consideration the views of women who see the issues differently. In fact, much of the conclusion of this dissertation, presented in Chapter Four, draws on input from women who view physician aid

in dying differently from how they view abortion. Ultimately, their contributions moved my thinking well beyond my initial paradigm. This research has pushed me to re-conceive the right-to-die movement as a broader end-of-life movement modeled on the reproductive justice framework.

Overview

Chapter One of this dissertation presents background information on the right-to-die movement, discusses the potential value of exploring similarities and differences between reproductive freedom and self-directed dying, suggests how dying might be a gendered experience, locates the two issues in the context of the evolving American concept of individual autonomy, and describes the multi-disciplinary research methods employed in this project. Chapter Two uses conceptual analysis to explore various ways autonomy has been understood by women, especially in their considerations of reproductive freedom and self-directed dying. Chapter Three presents a comparative analysis of documents, strategies, and conceptual frameworks employed in the reproductive freedom and right-to-die movements. Chapter Four uses oral histories to examine the extent to which veterans of the reproductive freedom movement recognize and find meaningful the similarities between reproductive freedom and self-directed dying, and to explore how they might, or might not, be inclined to shape the evolving right-to-die movement.

In total, this dissertation demonstrates that there are substantive connections between the issues at stake, the philosophical frameworks adopted, and the strategies employed in the reproductive freedom and right-to-die movements. Further, it examines the extent to which reproductive freedom veterans find these connections to be meaningful. Finally, it suggests how their perspectives might inform the modern right-to-die movement.

Background

The popular movement for abortion took hold in the late 1960s and early 1970s when the U.S. population was experiencing a falling birth rate, later marriage and childbearing among young women, rising college and labor force participation among women, a rising divorce rate, an increase in female-headed households, continued low wages for women, and a civil rights movement and an anti-war movement which asserted that ordinary people could take power over their own lives.[1] These conditions produced an increased need for abortion and helped catalyze women to fight for their own liberation including control over their own reproduction.

The popularization of the U.S. right-to-die movement, the emergence of which can be traced to the late 1970s and 1980s, also took place under a historically specific set of circumstances. By the 1970s, not only were fewer people dying of infectious diseases and more dying from long-term chronic diseases after living to increasingly older ages, but medical advances were

making it possible to keep seriously ill and even comatose people alive years longer than would have been the case in earlier decades.[2] Furthermore, while death, like birth, used to occur primarily at home, most people now died in the hospital, often in the course of receiving expensive and often distressing treatments to prolong life at virtually any cost.[3]

The case of Karen Ann Quinlan, whose parents successfully fought to remove their comatose daughter from a mechanical ventilator in 1976, became a matter of national attention.[4] In 1978, Derek Humphry published *Jean's Way*, an account of helping his terminally ill first wife take her own life.[5] He began receiving letters from people asking for similar assistance. In response, he and his second wife Ann Wickett established the Hemlock Society in 1980; the Hemlock Society promoted what it called voluntary "active euthanasia," or, more specifically, assistance from physicians who could provide a lethal dose of drugs to people wanting to hasten their own death.[6] By 1991 the Hemlock Society had over 25,000 members.[7] In that year, before medical aid in dying was legal in any state or country, Humphry wrote *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying.* Rejected by mainstream publishers, this how-to book was self-published by the Hemlock Society and shot to the top of the *New York Times* Best Sellers list.[8] In 1990, Jack Kevorkian's "suicide machine" captured public attention.[9] Also in that year, Nancy Cruzan's parents won a protracted legal battle to remove her feeding tube and let her die after she had been in a persistent vegetative state since being injured in an automobile

accident seven years earlier.[10] In 1991, Dr. Timothy Quill published an article in the *New England Journal of Medicine* detailing his decision to illegally provide a terminally ill patient a lethal dose of medication that she could self-administer if she so desired.[11] In 1994, Oregon voters approved Ballot Measure 16, the Death with Dignity Act, making Oregon the first state to legalize physician aid in dying.[12] Opponents, led by a lawyers from the National Right to Life Committee, which also opposed abortion, however, obtained a legal injunction preventing implementation of the Act. In 1997, the Oregon legislature placed a measure to rescind the Act on the ballot. In October of that year, the Ninth Circuit Court of Appeals lifted the injunction, and a week later voters rejected the attempt to repeal the Death with Dignity Act, making Oregon the first state in which aid in dying was provided legally.[13]

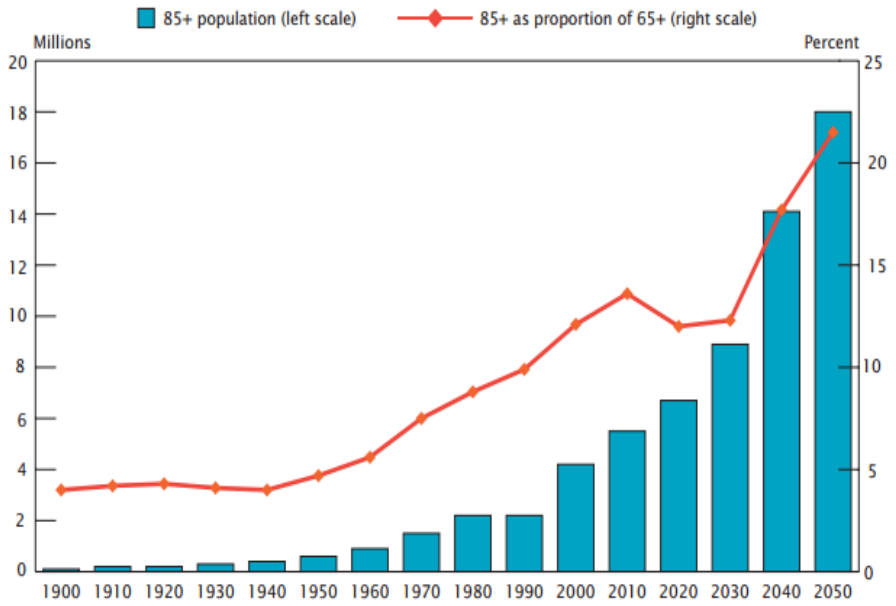
It was in the context of these recent and current events that explicitly feminist writers began addressing the future possibilities of active aid in dying and euthanasia. In their 1996 article, “A Feminist Exploration of Issues around Assisted Death,” Jocelyn Downie and Susan Sherwin wrote that the principal argument in favor of a permissive policy regarding self-directed dying was one of respect for autonomy.[14] The practical applications of patient autonomy at the end of life apply to both men and women, yet for reasons explained below dying may often be a gendered experience.

If, indeed, women might face particular end-of-life challenges, could that call feminists to offer insights into the conditions necessary to support self-determination throughout the lifespan, including at the end of life?

Relevance

In all the states (Oregon, Washington, Vermont, Montana, California, and Colorado) and countries (Switzerland, Holland, Luxembourg, Belgium, and Canada) in which aid in dying is practiced legally, available evidence suggests that the vast majority of people seeking aid in dying are at the end of life due to terminal illness, extreme old age, or both. In the U.S., more and more states are considering liberalizing assisted dying laws. This trend may continue as the population ages. Our ability to prolong the quantity (if not always the quality) of life has increased. As Figure 1 illustrates, there are now more people age 85 and older in the U.S. than ever before; by 2050 the total number may reach 18 million. Among people age 65 and older, the proportion 85 and older has doubled since 1960, and that proportion is expected to surpass 20 percent by 2050.

Figure 1: Population Aged 85 and Over, 1900 to 2050 [15]



Everyone will die, yet traditional gender roles regarding caregiving, women's relatively low economic status, and differing life expectancy rates between women and men may combine in ways that lead women and men to experience end-of-life issues in different ways.

Gender-Based Caregiving Disparities

Caregiving, including eldercare, is a highly gendered responsibility in U.S. families. Families provide more than 80 percent of long-term care, and 75 percent of unpaid caregivers are female.[16] When people need ongoing care during a long dying process, women are disproportionately likely to be their care provider.[17] Women typically marry men, and on average the men they marry are older. Men have a shorter life expectancy than women. It is not surprising, therefore, that wives constitute approximately two-thirds of spousal assistants at the end of life.[18] And, when older parents or other non-spouse family members

need assistance, it is disproportionately likely to be provided by female relatives.[19] While many individuals have positive feelings about their caregiving roles, there are significant psychological, physical, and economic costs to caregivers.[20]

Gender-Based Financial Disparities

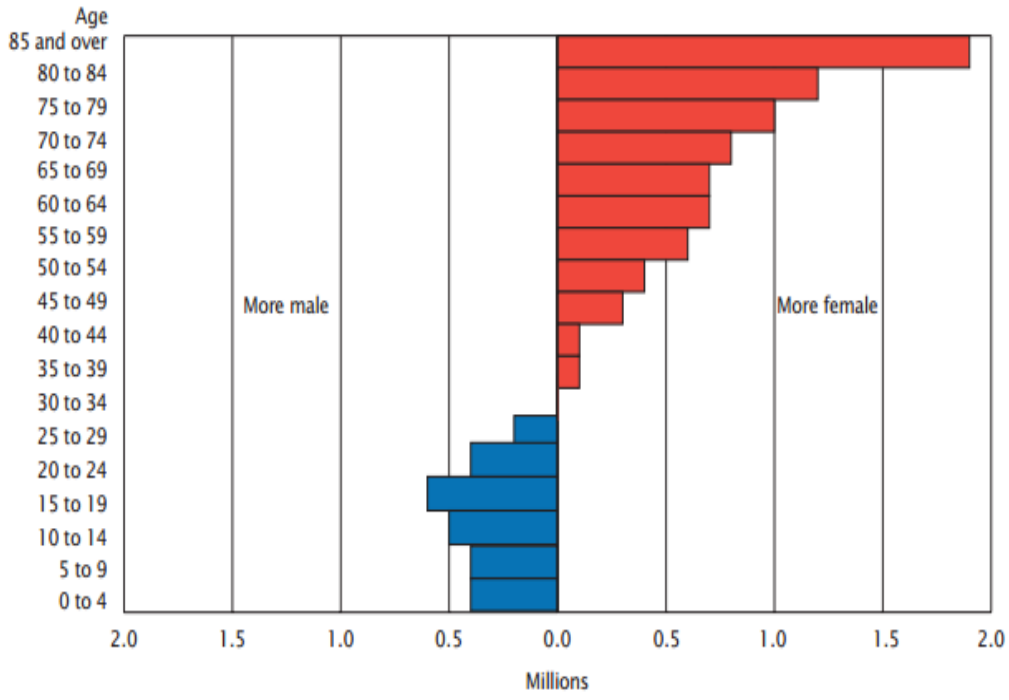
The wage gap between women and men is well documented. Employed women who also function as family caregivers frequently suffer additional decreased earning potential as they struggle to balance work and family responsibilities.[21] This can leave them less likely to have adequate financial resources in later life.[22] Furthermore, health care spending generally increases with age, and husbands, who are typically older than their wives, live those more expensive years and therefore use related financial resources before their wives do.[23] In addition, annual health care expenses for men from their early 60s onward are typically higher than are health care costs for women of the same age.[24] At the end of life, women are generally poorer than men and they are simultaneously less likely than men to have a spouse to care for them.[25] This may help explain why the vast majority of residents in Medicaid/Medicare-funded nursing homes are women.[26]

Gender-Based Life Expectancy Disparities

As Figure 2 shows, in 2010, women age 85 and older outnumbered men aged 85 and older. Projections through 2050 indicate that the gender gap in life

expectancy will continue at least through the next four decades. There are, and for the foreseeable future will continue to be, more old women than old men.

Figure 2: Differences between Male and Female Populations by Age, 2010[27]



Virtually all of the women who led the fight for abortion rights in the 1960s and 1970s came to the political work of promoting safe, accessible, affordable abortions because of their own personal experiences. Many had, themselves, faced unwanted pregnancies and sought illegal abortions. Others had helped friends and family members obtain abortions. These women who worked to achieve greater autonomy for women in their reproductive lives are now in their 60s, 70s, and 80s. (See circled sex/age cohorts in Figures 3-6 on the following pages.)

Figure 3: Population by Age and Sex, 1970[28]

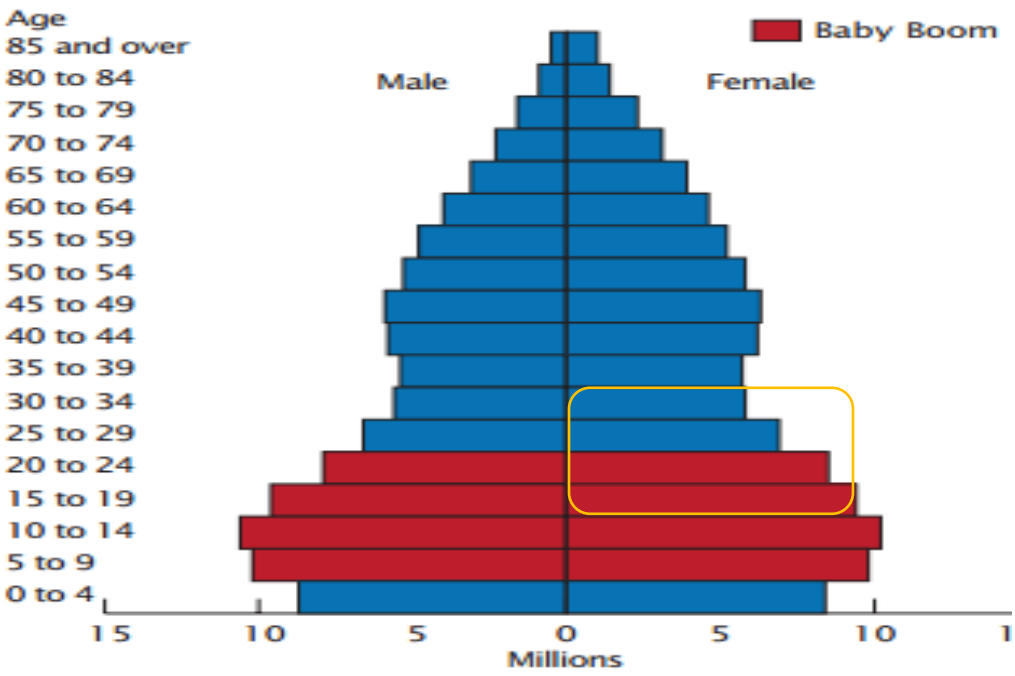


Figure 4: Population by Age and Sex, 2010[29]

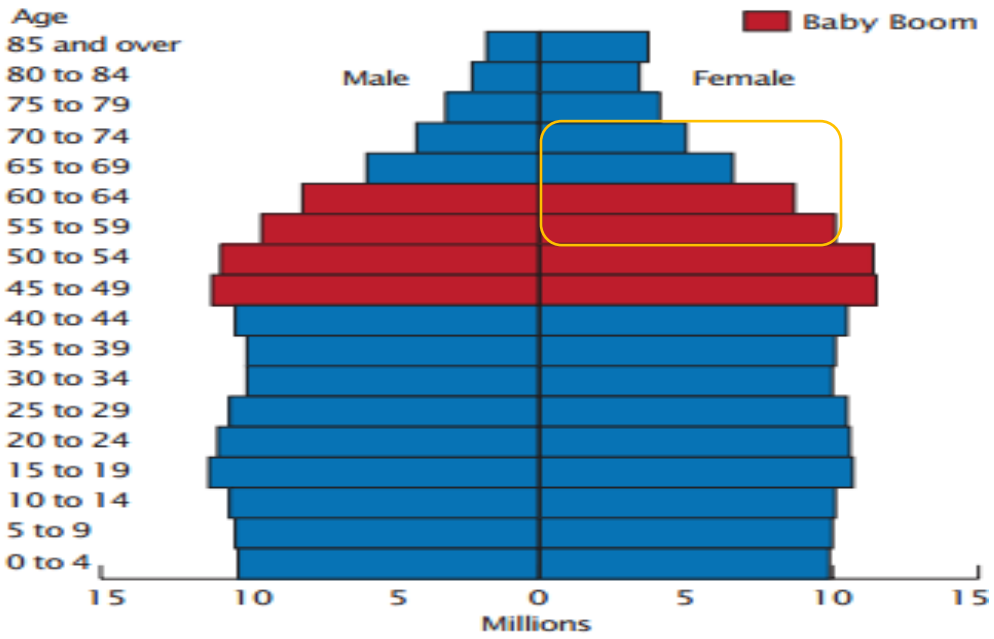


Figure 5: Population by Age and Sex, 2030[30]

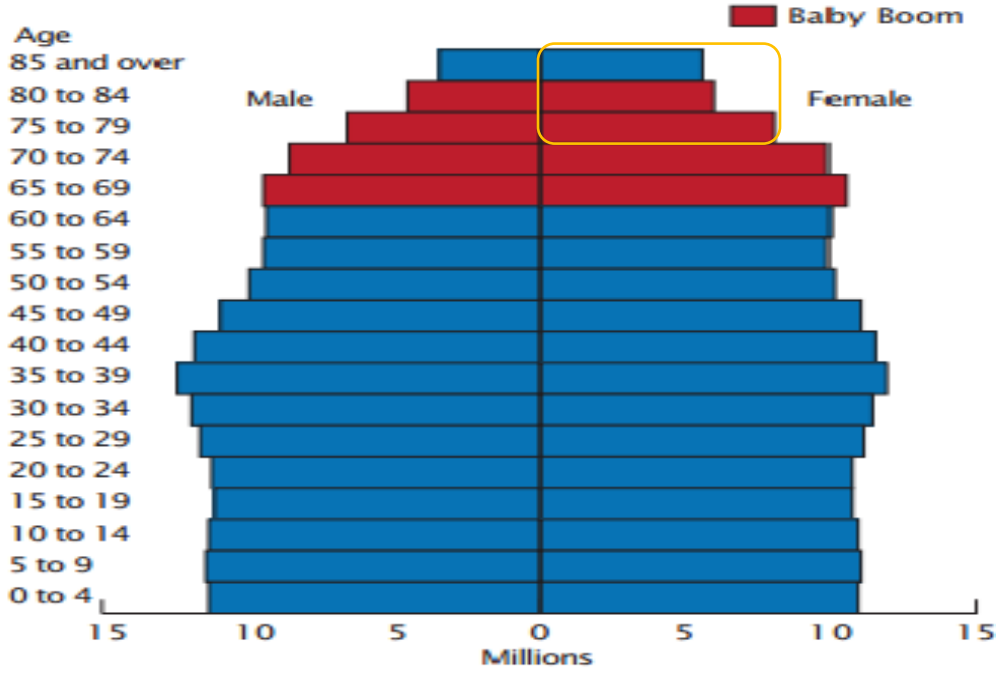
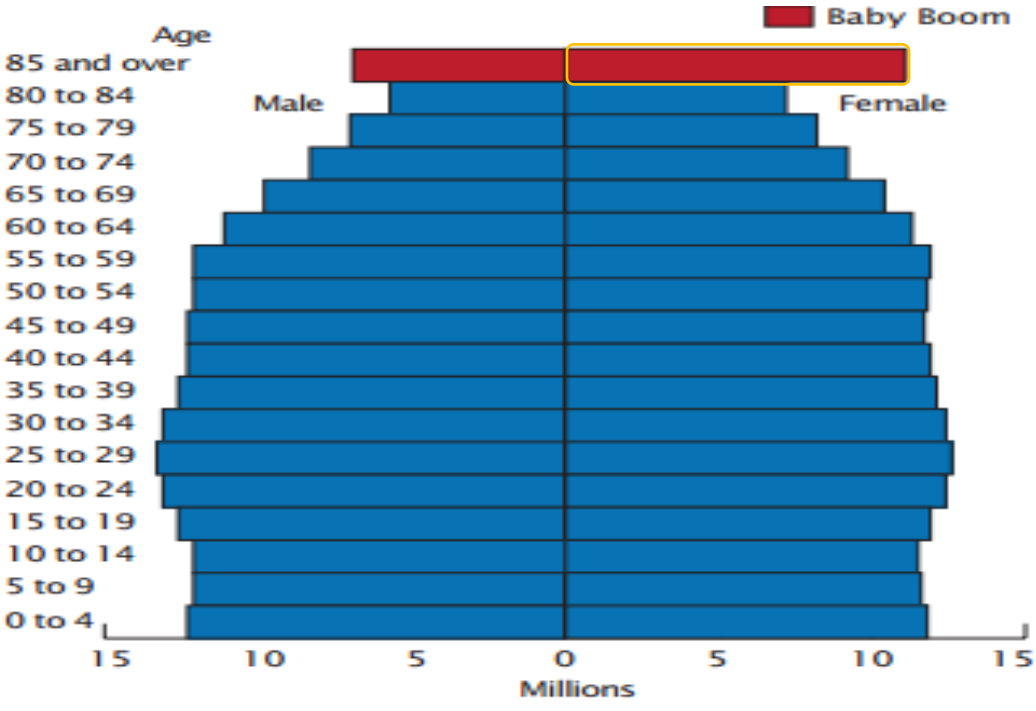


Figure 6: Population by Age and Sex, 2050[31]



Few of the veteran reproductive freedom activists in this age cohort have yet faced their own end-of-life decisions, but many have cared for aging and dying parents or other relatives or friends. Each of the veteran reproductive freedom activists interviewed for this project related stories of caring for friends or family members at the end of life. Just as their personal experiences with issues of reproduction helped shape their abortion rights work in the 1960s and 1970s, their personal experiences with issues of death and dying may help shape their end-of-life attitudes and activism today and in the future.

Over the next four decades, the majority of these women are likely to face their own extreme old age, their own approaching death, or both. During their potential childbearing years they fought for more control over whether, when, and how they reproduced. Now that they are approaching, entering, or experiencing old age and the inevitable end of life is growing closer, might these same women fight for more control over when and how they die? And if so, how might they engage with, and perhaps shape, the evolving right-to-die movement?

Although senior women who are veterans of the reproductive freedom movement may have important insights into what autonomy could, and should, mean at the end of life, there is no literature addressing their perspectives. This dissertation aims to fill that research gap. The specific research questions addressed here are:

- How might, or might not, highlighting the parallels between the struggle for abortion and the struggle for self-directed dying draw support from

Baby Boomer veterans of the reproductive freedom movement for the right-to-die movement?

- How might the lessons of the reproductive freedom movement inform the right-to-die movement?

Framework

To begin to answer these questions, I conducted interviews with ten women, each of whom had a significant background leading or contributing to the reproductive freedom movement and/or had had an abortion before *Roe v Wade*. The baseline criteria were that each woman interviewed 1) was of childbearing age prior to the 1973 *Roe v. Wade* U.S. Supreme Court decision that vastly expanded the availability of legal abortions, and 2) supported a woman's access to abortion.

In order to provide interviewees with the insight I had gained at the ACLU staff meeting described above before we spoke, I mailed each a brief list of similarities between the abortion movement of the 1960s and 1970s and the right-to-die movement today. The mailing also included a list of questions, some about the differences women saw between the two issues.[3] Interviews were conducted using an oral history format in which women were encouraged to talk about experiences in their personal and professional lives that they believed

[3] A discussion of parallels is included in Chapter Three, and interviewees' comments on differences appear in Chapter Four.

influenced their thinking about self-directed dying. The construction of interview procedures and the analysis of interview data were based on an interdisciplinary approach. This approach was interpretive in that it sought to illuminate the role of autonomy in self-directed dying from the perspective of each woman interviewed. It was also critical in that it sought to identify and critique inequalities that might enhance or diminish autonomy at the end of life. The research approach also drew on grounded theory to the extent that it sought to develop, rather than to prove or disprove, a theory about how veteran reproductive freedom activists might engage with and perhaps shape the right-to-die movement. Finally, the research and analysis employed a feminist approach as they focused on the experiences of women and drew on feminist literature (especially feminist concepts of autonomy); in addition, all the women interviewed identify themselves as feminists and are recognized as feminist leaders.[4]

[4] This dissertation uses the terms “woman” and “women.” In recent decades scholars and activists have argued that gender is socially constructed and that a binary system of gender assignment fails to reflect the diversity of people whose gender identification and expression are not included in a meaningful way in such a restrictive paradigm. I agree. My use of the terms “woman” and “women” here is not meant to exclude trans women, trans men, or gender-fluid people. The terms are useful, however, in part because the people I interviewed, who are now in their 60s, 70s, and 80s, grew up thinking of themselves as “women” at a time

The feminist framework of this dissertation is guided by the definition of modern feminism offered by Estelle Freedman in *No Turning Back: The History of Feminism and the Future of Women*. Feminism, she says, is based on " . . . a belief that women and men are inherently of equal worth."[32] "Because most societies privilege men as a group," she explains, "social movements are necessary to achieve equality between women and men, with the understanding that gender always intersects with other social hierarchies."[33] This dissertation is further guided by the conclusion of Jocelyn Downie and Susan Sherwin in their article, "A Feminist Exploration of Issues around Assisted Death," that " . . . a feminist analysis supports a permissive policy with respect to assisted death, provided that care is taken in establishing the policy to avoid increasing (or failing to decrease) the oppression of women and other oppressed groups."[34]

One underlying assumption of this project is that women who actively participated in the reproductive freedom movement can bring a valuable perspective to the role of individual autonomy in self-directed dying. Another is that "the personal is political"; specifically, that the personal experiences of women interviewed for this dissertation might inform their future political activism.[35] As noted in the Preface, this dissertation builds on interviews I conducted in the 1980s with veteran reproductive freedom activists who pioneered the abortion movement in the 1960s and early 1970s. A review of their

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when abortion was often considered to be a "women's issue" and was frequently advocated for within the context of a "women's liberation movement."

work is presented in Chapter Three. First published in *Abortion without Apology,* these interviews describe how women mentioned below—Patrician Maginnis, Lana Clarke Phelan, Rowena Gurner, and Carol Downer—survived personal experiences with illegal abortions, experiences that led them to their political work.[36] Similarly, interviews with Laura Kaplan, Lucinda Cisler, and Lorraine Rothman, also published in *Abortion without Apology,* describe how the political, social, and economic conditions of the late 1960s and early 1970s influenced these women to join the abortion movement.[37] Their interviews provide a humanizing bridge between 1) the broad social conditions mentioned above in which the popular abortion movement emerged, and 2) the real-life experiences of some of the women who would eventually become activists in the abortion movement.

By the time I interviewed Maginnis, Phelan, Gurner, Downer, Kaplan, Cisler, and Rothman in the 1980s, however, the abortion movement of the 1960s and 1970s was already history. Today, as will be shown below, the contemporary right-to-die movement in many ways parallels the abortion movement of the 1960s and 1970s. This dissertation offers the personal experiences of veteran reproductive rights activists regarding death and dying as individual narratives illustrating and occurring within the broad social conditions in which the emerging right-to-die movement is unfolding. Just as the personal experiences of women of previous decades illustrated the social conditions that gave rise to the abortion movement of the 1960s and 1970s and ultimately shaped that movement, the

much more recent personal experiences of reproductive freedom advocates regarding death and dying presented in this dissertation provide real-life examples of how the social conditions impacting end-of-life decisions are experienced in the personal lives of women, and how their personal experiences might influence their political activism on right-to-die issues.

This study has strengths and limitations. A possible limitation is the fact that Chapter Four includes new interviews reflecting the insights of only ten women. These same ten women are also one of its strengths for three reasons—their diversity, their expertise, and their ability to influence other women. Although their insights are not generalizable across the population at large, they offer significant new perspectives that could help shape the evolving right-to-die movement.

My selection of women to interview was guided by my appreciation of the reproductive justice framework, a framework developed and used by women of color. I determined that I would interview at least as many women of color as white women. Because I was focusing on the similarities and differences between issues of self-directed dying and reproduction, and because I knew that African-Americans, Puerto Ricans, and Native Americans had experienced sterilization abuse and other reproductive injustices, I sought out women from these groups who were knowledgeable about this history and who might offer a variety of ideas about the parallels between the two movements. And, because I knew that many women living with disabilities had experienced similar injustices,

and that many disability rights advocates oppose legal aid in dying, I determined that I would interview at least two women living with, and/or caring for others living with disabilities. While I thought it important to included diverse women, however, I did not expect them to represent all women of a specific ethnic or experiential background, nor did they put themselves forward as doing so.

Because of my own background as an activist, and because of the research I had done on the history of the abortion movement, I knew of many activists and organizations I could reach out to for assistance in identifying and recruiting potential interviewees. Fortunately, I had developed a reputation as trustworthy researcher and movement colleague. In the 1980s, after interviewing early abortion leaders, I made their interviews available as reproductive freedom organizing tools by featuring them in *Abortion without Apology* and the companion film documentary *With a Vengeance: The Fight for Reproductive Freedom,* which I co-produced. We used these tools as I continued to work with interviewees and their larger networks to support reproductive freedom. Consequently, many activists who knew me or my work were willing to help me identify and recruit new interviewees for this project.

The final interview pool consisted of ten women from a range of economic and experiential backgrounds. Five are women of color, one lives with a disability, and one is the primary caregiver for a child living with a disability. Interviewees come from Hawaii, California, New Mexico, South Dakota,

Montana, New York, New Jersey, and Georgia. Their diversity adds to the richness of this study.

I assured all interviewees that, just as *Abortion without Apology* had been a collaboration built on trust, I would bring that same ethic to this project. Specifically, I assured them that I would send them a copy of any writing for comment before submitting this dissertation or publishing, and that I would not use any information that they asked to be kept confidential. After I had interviewed seven women, I had the opportunity to publish a short article about this work in *The Women's Health Activist,* the newsletter of the National Women's Health Network. I shared a draft of the article with interviewees prior to publication, and benefited from extensive revisions suggested by one interviewee in order to better reflect her perspective. More recently, I shared a draft of this dissertation with all ten interviewees. Several offered suggestions and corrections that have improved the accuracy and integrity of this document.

This study benefits not only from the diversity of the women interviewed but also from their expertise and ability to influence other women. As will be shown in Chapter Four, all interviewees have extensive backgrounds working for women's rights and civil and human rights, and most are recognized leaders of the reproductive freedom movement. They are published authors, sought-after speakers, organizational founders or directors, and/or thought leaders or policy makers. Each is influential in a broad network of women activists. Because of their connections to vast numbers of other women, their input into this project is

informed by their work with many diverse groups of women, making it especially valuable. At the same time, their response to the process of participating in this project has the potential to influence the thinking of the vast numbers of women to whom they are connected.

This study, undertaken within the context of American Studies, benefits from the American Studies approach in at least five ways. First, by its nature, American Studies is inter-disciplinary. This work draws on multiple disciplines including history, philosophy, bioethics, and health policy. Second, American Studies acknowledges that there are many American experiences, most of which are at least partially informed by class, gender, race/ethnicity, and other issues. This document incorporates the voices of American women from diverse backgrounds. Third, American Studies allows for a variety of research methods, and as described above, the research underpinning this dissertation draws on a variety of methods. Fourth, because autonomy is a key—yet contested—concept in American culture, American Studies lends itself to a study that examines questions about the nature, value, and limitations of autonomy and the conditions necessary to support self-determination. Fifth, the discipline encourages questions about why the right-to-die movement has evolved differently in the U.S. than in other jurisdictions. For these reasons, the discipline of American Studies provided an appropriate context for the project I envisioned. At the same time, this study makes an original contribution to American Studies. A review of the literature reveals that few if any American Studies publications have addressed

assisted dying in America. This dissertation begins to fill that gap. It combines American reproductive freedom history with research on contemporary attitudes towards self-directed dying in a new way to navigate the cultural terrain between abortion rights and reproductive justice on one hand and self-directed dying on the other.

Autonomy

Autonomy is a key concept in American history and culture. In establishing the United States, the founding fathers rejected subjugation to England and formed the new country as a sovereign, autonomous nation. The new nation would be a democracy and as such it would depend upon (some of) the people to make policy. That, in turn, would require those policy-making citizens to understand themselves as being in some sense self-directing, or autonomous. Autonomy at the national level would be supported by autonomy at the personal level.

The word “autonomy” is derived from Greek and is generally understood to refer to a state of being self-directed, free from coercion by outside influences. It is closely related to liberalism, derived from the English term “liberal,” which initially referred to a class of “free men.”[38] “Autonomy” also carries with it the connotation of individuals having inherent dignity and value, of being self-authenticating sources of valid claims.[39]

When the U.S. was founded in 1776, however, only a small portion of the population was recognized as autonomous. Black women and men, for example, could be held in slavery. Then, and for nearly another century, they were not even seen as fully human by the law and by much of the white public. Slavery was not abolished until 1865, and black men were not accorded the right to vote until 1870. Women of any race began winning the vote in territories and states in the late 19th Century and national women's suffrage was not exacted until 1920.

White women were not enslaved. However, under the common law that had existed since English settlement of North America, married women were not seen as independent entities apart from their husbands. Under the system of coverture, they often could not own property or enter into contracts. Coverture laws were substantially modified in the 1800s, but aspects of these laws existed in various forms in some states until the 1960s.

One aspect of the feminist project over time has been to increase women's autonomy. Historically, mainstream U.S. feminists have worked not only to end coverture and win suffrage but also to enable women to train for and enter into professions that would afford them economic independence, thus reducing their dependence on men. Similarly, feminists have fought (and are still fighting) for the right to control their own reproduction, thereby increasing their ability to control their own life experiences, their own autonomy. The feminist struggle not only to attain but in fact to redefine autonomy, as shown in Chapter 2, is but one example of the efforts of people not seen as autonomous in 1776 (including

women, people of color, the poor, and people living with disabilities, among others) to gain entry to the democracy proposed by the founding fathers of the United States of America.

[1] Rosalind Pollack Petchesky, *Abortion and Woman's Choice: The State, Sexuality, and Reproductive Freedom* (Boston: Northeastern University Press, 1984).

[2] Margaret Battin points out that these developments took place against a backdrop of an increasing emphasis on individual rights, declining religiosity among Americans, and changing religious attitudes toward death, thus setting the scene for the popular movement to promote self-determination at the end of life. See Margaret Pabst Battin, Safe, Legal, Rare? Physician-Assisted Suicide and Cultural Change in the Future," in *Ending Life: Ethics and the Way We Die* (New York: Oxford University Press, 2005), 324.

[3] It was not until the middle of the 20th century that the majority of people died in hospitals or nursing homes; by the 1980s, only 17% died at home. See Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Picador, 2014), 6, and Endlink, *End of Life in America,* http://endoflife.northwestern.edu/introduction/what.cfm#Preferences vs. Realities.

[4] Katharina C Heyer, "Rejecting Rights: The Disability Critique of Physician Assisted Suicide," in *Special Issue Social Movements/Legal Possibilities (Studies in Law, Politics and Society)*, ed. Austin Sarat (Emerald Group Publishing Limited, 2011), 82-83.

[5] Derek Humphry, *Jean's Way* (New York: Quartet Books, 1978).

[6] Elaine Fox, Jeffrey J Kamakahi, and Stella Čapek, *Come Lovely and Soothing Death: The Right to Die Movement in the United States* (New York: Twayne Publishers, 1999), 28.

[7] Ibid., 29.

[8] Lawrence K. Altman, "How-to Book on Suicide Is Atop Best Seller List," New York Times, http://www.nytimes.com/1991/08/09/us/how-to-book-on-suicide-is-atop-best-seller-list.html.

[9] Brian Meehan, "Suicide of Portland's Janet Adkins with Kevorkian's Help Brings Euthanasia Issues into Spotlight," http://www.oregonlive.com/health/index.ssf/1990/06/portlands_janet_adkins_suicide.html..

[10] Heyer, "Rejecting Rights: The Disability Critique of Physician Assisted Suicide," 83.

[11] Timothy Quill, "Death and Dignity - a Case of Individualisd Decision Making," *New England Journal of Medicine*, no. 324: 691-94.

[12] Oregon Health Authority, "Death with Dignity Act," https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf.

[13] Oregon.gov., "Death with Dignity Act History," http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/history.pdf.

[14] Jocelyn Downie and Susan Sherwin, "A Feminist Exploration of Issues around Assisted Death," *St. Louis University Public Law Review* 15, no. 2 (1996): 314.

[15] U.S. Census Bureau, "65+ in the United States: 2010," (Washington, DC: U.S. Government Printing Office, 2014).

[16] Laura Katz Olson, *The Not-So-Golden Years: Caregiving, the Frail Elderly, and the Long-Term Care Establishment* (New York: Rowman and Littlefield, 2003), 52.

[17] Ibid.

[18] Ibid.

[19] Ibid., 53.

[20] Ibid.

[21] Family Caregiving Alliance, "Women and Caregiving: Facts and Figures," https://www.caregiver.org/women-and-caregiving-facts-and-figures.

[22] Ibid.

[23] Dale H. Yamamoto, "Health Care Costs--from Birth to Death," Society of Actuaries, http://www.healthcostinstitute.org/files/Age-Curve-Study_0.pdf.

[24] Ibid.

[25] Susan Wolf, "Gender, Feminism and Death: Physician-Asisted Suicide and Euthanasia," in *Feminism and Bioethics: Beyond Reproduction*, ed. S. Wolf (New York: Oxford University Press, 1996), 304.

[26] Centers for Disease Control and Prevention, "National Nursing Home Survey," National Center for Health Statistics, https://www.cdc.gov/nchs/data/nnhsd/Estimates/nnhs/Estimates_PaymentSource_Tables.pdf#Table08.

[27] U.S. Census Bureau, "65+ in the United States: 2010," 12.

[28] Ibid., 10.

[29] Ibid.

[30] Ibid.

[31] Ibid., 11.

[32] Estelle B. Freedman, *No Turning Back: The History of Feminism and the Future of Women* (New York: Ballantine, 2002), 7.

[33] Ibid.

[34] Downie and Sherwin, "A Feminist Exploration of Issues around Assisted Death," 329-39.

[35] Alice E. Ginsberg, *The Evolution of American Women's Studies: Reflections on Triumphs, Controversies, and Changes* (New York: Palgrave Macmillan, 2008), 69.

[36] Baehr, *Abortion without Apology: A Radical History for the 1990s*.

[37] Ibid.

[38] Nikhil Pal Singh, "Liberalism," in *Keywords for American Cultural Studies*, ed. Glenn Hendler Bruce Burgett (New York: New York University Press, 2007), 139.

[39] Susan Williams, *Truth, Autonomy, and Speech: Feminist Theory and the First Amendment* (New York: New York University Press, 2004), 20.

CHAPTER TWO

AUTONOMY IN FEMININE AND FEMINIST ETHICS AND SELF-DIRECTED DYING

Autonomy in Feminine and Feminist Ethics

A discussion of women's theorizing about autonomy is relevant to a discussion about women's views on and potential decisions about self-directed dying because, as will be shown below, arguments in favor of self-directed dying are frequently based on the assumption that autonomy is a value that is important and positive. Women's theorizing has not existed in a vacuum, and women seeking to define autonomy in ways that respect and may serve to improve women's experiences have drawn on historical notions of autonomy. To Aristotle, an autonomous action was one that was voluntary, by which he meant an action taken based on a desire originating inside a person and free from external coercion.[40] Later liberal philosophers such as Thomas Hobbes, John Locke, Immanuel Kant, John Stuart Mill and others posited versions of autonomy (often described as freedom, liberty, self-ownership, etc.) consistent with Aristotle's equation of autonomy with freedom from external coercion. Autonomy is a key concept in moral as well as political theories.

Discussions of what autonomy means for women have been critical to feminists' explorations of women's psychology, identity, and ethics. For example, in her book, *Feminine and Feminist Ethics*, Rosemarie Tong describes a

feminine approach to ethics as being interested in the ethical implications of the allegedly feminine values of care and connectedness (as opposed to the allegedly male value of individualism), and a feminist approach to ethics as being concerned with promoting women's emancipation.[41] She states, "A number of thinkers, not all of them 'feminine' or 'feminist,' complain that the self that grounds traditional ethics is an 'excessively individualist' self—a self that takes a measure of delight in separating *himself* from others."[42] She explains, "Most people picture autonomous man as a biological male: an independent self, geared toward maximizing his self-interest effectively, efficiently, and expediently."[43] "Such a self," she says, "is always on guard against the ominous 'other' who, at any moment, may interfere with his life projects."[44] Tong goes on to say, "Ontology became a matter of separating the self from the other, and ethics became a matter of defending one's own interests from that of others."[45] This individualistic approach to autonomy has not always served women well, however, both because women have often had to depend upon men, and because children and others often depend upon women.

In the 18th and 19th centuries women such as Mary Wollstonecraft, Harriet Taylor, Catherine Beecher, Elizabeth Cady Stanton, Charlotte Perkins Gilman and many others reflected upon whether women's sense of morality may be different from that of men. A watershed moment in 20th century feminism came when Carol Gilligan published *In a Different Voice: Psychological Theory and Women's Development* in 1982.[46] In what publisher Harvard University Press

called “the little book that started a revolution,” Gilligan refuted the conclusions of Lawrence Kohlberg, who had implied that women’s moral development was inferior to men’s.[47] Gilligan argued that women’s moral development was different from but not inferior to men’s. She suggested that, overall, it was based less on individualism and abstract notions of justice and more on relatedness to other people and to the particular conditions in which they found themselves.

Two years later, in 1984, Nel Noddings published *Caring: A Feminine Approach to Ethics and Moral Education.*[48] Referencing links between motherhood and caring, Noddings agreed with Gilligan that women’s sense of morality emphasized their relationships and the particular life circumstances of the people for whom they cared. The work of Gilligan and Noddings as well as that of other “cultural feminists” gave rise to ideas of the “ethic of care,” “relational ethics,” and “feminine ethics.”

Feminine and feminist ethics have raised questions that go to the core of what autonomy means for women. The next section of this dissertation will address how scholars have applied feminine and feminist ethics to the issue of self-directed dying. Meanwhile, the broader debate about what autonomy means for women continues. As one example, Amy Allen’s book *The Politics of Ourselves: Power, Autonomy, and Gender in Contemporary Critical Theory*, explores the views of critical theorists who understand the self as constituted by power relations, and perhaps as consequently almost incapable of autonomy. It also presents the views of those who see the self as also possessing

autonomous capabilities for reflection and transformation. Allen quotes Seyla Benhabib as asking, if the self is totally socially constructed, "…how in fact the very prospect of female emancipation would even be thinkable without . . . agency, autonomy, and selfhood?"[49]

As another example, in *Truth, Autonomy, and Speech: Feminist Theory and the First Amendment*, Susan Williams discusses the threats posed by social constructionism. She writes, "The absence of autonomy threatens to so 'decenter' the subject or self that the concept of 'woman' will become useless as the basis for theory or for political organization."[50] She goes on to say that, "… the critique of autonomy may also leave us with a self-image of victimization that is neither appealing to all the women who need the movement nor effective as a basis for political organizing."[51]

Williams proposes an alternate view of autonomy, which she calls "narrative autonomy," in which a person orders her understanding of events or relationships or concepts in a way that creates or reveals personal meaning. She points out that this meaning need not concern only oneself, as the meaning of one's life could be fundamentally connected with other people or a belief system. "Thus," she explains, "a person would review her personal history, weighing the particulars of (her) past in terms of more general moral values, and discerning a course of action which expresses a commitment to these particulars."[52] "The model of narrative autonomy" she concludes, "is relational in all the senses required by the feminist critique of liberal autonomy."[53]

Feminist and Feminine Ethics and Self-Directed Dying

As explained above, explicitly feminist writing about self-directed dying was first published in the 1990s at a time of growing public interest in topics including the rejection or removal of life-prolonging medical treatment, medical aid in dying, and euthanasia. Medical aid in dying of any kind was not yet legal anywhere in the U.S., or, technically, in the world, although it was being practiced in the Netherlands, as explained below. Thus, it was in the context of those public debates, and at a time when feminine and feminist ethics were first being applied to both long-established and relatively new disciplines, such as bioethics, that the feminist discussion specifically about the then-illegal practices of physician aid in dying and euthanasia took place. This debate is worthy of attention today in part because of the ways in which feminist writers of that decade built on and responded to one another's arguments.

Perhaps the earliest explicitly feminist article addressing self-directed dying, "A Feminist Analysis of Physician-Assisted Dying and Voluntary Active Euthanasia," was published by Leslie Bender in the *Tennessee Law Review* in 1992.[54] Bender concluded that, given certain guidelines, physician aid in dying and voluntary euthanasia for terminally ill patients could be empowering and consistent with patient autonomy.

Four years later, in 1996, at least three feminist essays addressing physician aid in dying and euthanasia appeared. Sydney Callahan published "A Feminist Case against Euthanasia," in *Health Progress*.[55] A deeply religious

Catholic, Callahan opposed both abortion and physician aid in dying on the grounds that life is a gift that we have a moral obligation to preserve, but she also expressed concern that women might be particularly at risk of coercion should physician-assisted dying become legal. She argued that the devaluing of women relative to men had already led to inferior health care for women, pointed out that our society seemed to embrace a sexist double standard regarding its views of maturing and aging women compared to maturing and aging men, and worried that this sexist double standard might extend to disproportionate support for hastening death among old women. Another 1996 article, "A Feminist Exploration of Issues around Assisted Death," by Jocelyn Downie and Susan Sherwin, appeared in the *Saint Louis University Public Law Review.*[56] Like Bender, they supported physician aid in dying. Just as Downie and Sherwin's article went to press, Susan Wolf published "Gender, Feminism and Death: Physician-Assisted Suicide and Euthanasia." Like Callahan, Wolf argued against legalizing physician aid in dying, fearing that cultural views of women would make them more vulnerable than men to direct or indirect coercion to hasten death. In particular, she worried that our society's valorization of women's self-sacrifice might encourage women to disproportionately seek, and physicians to disproportionately provide, lethal doses of medication. She wrote, "Women in this country are differentially poorer, more likely to be either uninsured or on government entitlement programs, more likely to be alone in their old age, and more susceptible to depression."[57] "Those facts alone," she warned, "would spell

danger. But when you combine them with the long (indeed, ancient) history of legitimating the sacrifice and self-sacrifice of women, the danger intensifies."[58]

In 1997, Wolf further argued against legalizing physician aid in dying in her article, "Physician-Assisted Suicide, Abortion, and Treatment Refusal: Using Gender to Analyze the Difference."[59] In this article she reiterated her concern that legal physician aid in dying would result in death being hastened more often (and inappropriately) among women than among men. Wolf reviewed legal decisions related to providing abortions and withdrawing life-prolonging treatment, which she saw as fundamentally different from physician aid in dying. Unlike physician aid in actively hastening death, both abortion and the withdrawal of life-prolonging treatment involved protecting women from "unwanted bodily invasion." She wrote, "That invasion comes in many forms: incest and sexual abuse of girls, unwanted impregnation and pregnancy in women of reproductive age, rape of women of all ages."[60] "Thus for women," she argued," the right to exclude unwanted bodily invasion is absolutely fundamental."[61] But, she concluded, "None of the same can be said for the supposed right to be free to obtain bodily invasion to kill oneself."[62] In fact, Wolf's concern was that legalizing aid in dying might lead to women being overtly or covertly coerced into hastening death, a development that would constitute a new form of bodily invasion for women.

Wolf's description of the importance of freedom from unwanted bodily intrusion was eloquent, but other authors implicitly or explicitly continued to link control over one's body and, consequently, one's life experience, to issues not

only of control over the reproductive process but also to control over the dying process. In 1998, for example, Dr. Margaret Pabst Battin published “Physician-Assisted Suicide: Safe, Legal, Rare?” in the anthology *Physician Assisted Suicide: Expanding the Debate*, which she co-edited. Referencing President Bill Clinton’s assertion that abortion should be “safe, legal and rare,” Battin drew on similarities between birth control and self-directed dying.[63] Just as some feminists have rejected the idea that abortion is something negative that should, ideally, be rare, Battin did not automatically assume that physician aid in dying was negative. She asked whether, if legalized, physician aid in dying, like physician aid in controlling reproduction, might not become a widely accepted norm.[64]

Also in *Physician Assisted Suicide: Expanding the Debate,* Dena Davis furthered the analysis between control of our reproductive process and control of our dying process in her essay, “Why Suicide is Like Contraception: A Women-Centered View.” Pointing out that “ . . . an important piece of the feminist project is to argue that biology is not destiny,” she suggested that just as one could use contraception to reject “ . . . passive acceptance of what would happen to one’s life because of one’s bodily proclivities,” one could say, “My body’s continued capacity to pump blood and oxygen is no longer a good for my life but rather a threat to my values and interests in how the final chapter of my life is written; therefore, I will exert control by committing suicide.”[65] Critiquing a concern that Wolf raised in both the articles mentioned above, namely society’s view that women should be self-sacrificing (and might therefore be consciously or

unconsciously subject to manipulation toward suicide), Davis proposed an alternate view of self-sacrifice. In rejecting self-directed dying, she argued, a person might be expected " . . . to undergo long periods of pain and disability, perhaps even dementia, rather than do something as dramatic and unconventional as put an end to one's own life."[66] She stated:

> The ill or dying person is being asked to forgo acting on her own interests in order to 1) avoid making her relatives look like selfish, uncaring brutes in the eyes of the more conventional world; 2) refrain from challenging the comfortable belief that life is always worth living; and 3) avoid giving society at large a push down the slippery slope in the direction of callousness toward those sick and disabled people who do *not* wish to end their lives.[67]

"Thus," she concluded, "one could argue that those who oppose rational suicide are asking women to shoulder yet another traditional female burden; the preservation of society's moral and religious values."[68]

In her essay, Davis noted, "Suicide is always described negatively as a 'risk,' rather than as a 'response' or an 'option.'"[69] She went on to question Callahan's assertion that life is a "gift," explaining, "This notion of the self as the receiver of a gift that one is then stuck with, and yet does not *own*¸ casts the self as receptive and passive."[70]

The following year, in 1999, Diane Raymond published an article in *Hypatia* entitled, "'Fatal Practices': A Feminist Analysis of Physician-Assisted Suicide and Euthanasia," which directly critiqued Wolf's 1996 article. Raymond concluded that Wolf's dismissal of physician aid in dying was "premature" and argued, "A blanket prohibition against euthanasia, while clear and easy to

maintain, seems to me inconsistent with feminism's rejection of rigid absolutism and its embracing of context and ambiguity."[71]

With the exception of Callahan, all of the feminist authors cited above accepted autonomy as an important value. At the same time, they critiqued a solely rights-based construction of autonomy and raised questions about or provided examples of how traditional liberal concepts of autonomy could be reconciled with a more feminine relational ethic. For example, Sherwin and Downie wrote, "Whereas traditional liberal interpretations of autonomy construct selves as ideally isolated, independent beings, a relational interpretation understands selves to be relationally constructed."[72] Bender stated, "Autonomy, the power of an individual to control her own life and death, is as much a cornerstone of a care-based ethic as it is of modern medical ethics and legal practice."[73] She went on to say, "The differences are in the sources and meanings of autonomy. In a care-based ethic, individual autonomy is a process nurtured in a web of relationships and responsibilities instead of a static condition pre-existing them."[74] Bender explained, "The autonomy of an ethic of care can be melded with the autonomy concerns in a rights-based medical ethic, if it is understood to mean self-governing moral agency, rather than independent or self-contained decision making."[75] She concluded, "Self-governing in an ethic of care does not mean governing alone by abstract reasoning or distant observations, but means choosing options with respect to responsibilities, relationships, conversations, and dialogues with others."[76]

Downie and Sherwin explained, “The standard approach to an assessment of whether a particular decision is an autonomous one is to ask whether there are any external forces directly interfering with the choice.”[77] They went on to say, “A relational approach is much broader and asks whether there are any external or internal forces directly or indirectly interfering with the choice.”[78] Next, they suggested a need to attempt to resolve or ameliorate external and internal forces if possible, but argued:

> Once a best effort has been made at all of this, then a woman’s wish should be respected no matter what others may think of the consequences for her and even if her decision seems to be in response to oppressive social conditions. We believe that we ought to fight the forces of oppression and the sources of the force. However, we do not believe that this fight should be conducted at the expense of individual women; we should fight *for* women but not fight *the* women.[79]

Downie and Sherwin wrote, “Restrictive state policies that limit the ability of an individual to choose assisted death falsely presume that the state is in a better position than the individual to determine if continued life is a benefit to her.”[80] Thus, they said, “They violate autonomy in a very deep way on a matter that is of fundamental interest to many individuals.”[81] Downie and Sherwin concluded, “ . . . while there are many arguments in the literature that oppose a permissive policy with respect to voluntary assisted suicide and euthanasia, we do not find any sufficiently persuasive to justify such a profound intrusion into personal autonomy.”[82]

Implicitly or explicitly, all these authors made clear that their concerns about physician aid in dying and euthanasia stemmed in part or in whole from

fears that members of oppressed groups, including but not limited to women, would be further disadvantaged by legalization of active aid in dying. For example, Downie and Sherwin stressed that their " . . . support of a permissive policy on assisted suicide and euthanasia is conditional on its including regulations which make it explicit that no individual should be pressured to accept assisted death or be made to feel that this is the normal and preferred response to their condition . . . "[83] Bender began her essay by stating, "I am deeply committed to major systemic changes in the funding and delivery of health care in our nation. We need a national health care system to ensure no citizen is forced to make medical decisions based on the scarcity of funds or insurance."[84] Davis wrote, "Although I am a proponent of rational suicide, I am less convinced that the legalization of physician assistance is a good policy."[85] She continued, "The many concerns about the effect on the medical profession, and the move to HMOs, with their tendency to look to the cheapest solution to any problem, give me pause."[86] She further explained, "One can imagine that rather than being an option people have to ask for, even fight for a little, physician-assisted suicide becomes one more track onto which certain patients are shunted."[87] She stated, "A better approach would be to look for creative solutions that do not involve the medical profession, for example, lay support groups, end-of-life midwives, and so on."[88] "But," she concluded, "this approach assumes a robust and public debate that can shake off the taboo of suicide in the same fashion that we are shaking off the taboo of contraception."[89]

Feminism and Bioethics: Beyond Reproduction, which Susan Wolf edited in 1996 and in which her essay, “Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia” appeared, also included an article by Rebecca Dresser entitled, “What Bioethics Can Learn from the Women’s Health Movement.” In this essay Dresser wrote, “Some of the same social forces triggered the ‘bioethics movement’ and the women’s health movement, primarily a revolt against medical paternalism and its abuses.”[90] She explained, “Many of the women’s health movement’s values and goals coincide with those of the bioethics movement. A more humane, patient-centered health care system with less emphasis on acute, high-tech interventions is one shared aim.”[91] “Others,” she continued, “include promoting patient autonomy, greater access to health care, and a broader array of settings in which individuals may receive care.”[92] About the women’s health movement, she wrote that goals included “ . . . greater patient control and demedicalization of childbirth, menstrual extraction, and even abortion, if it is performed by qualified nonprofessionals.”[93] She went on to say, “Among more specific goals are the creation of health information centers for all consumers, more women’s health centers, more alternatives to nursing homes, and a better system of respite care for at-home caregivers.”[94] “Universal access to good health care,” she said, “is also a priority. In addition, the movement endorses antitrust and other challenges to the medical establishment’s effort to suppress alternatives such as home birth and midwifery.”[95]

Throughout the period in which these authors were writing, initiatives to legalize physician aid in dying went to the ballot in Washington and California, where they failed, and in Oregon. As noted above, in 1994 Oregon voters passed a ballot measure approving the Oregon Death with Dignity Act, which finally went into effect in 1997. At the time Bender, Downie, Sherwin and Wolf were writing, physician aid in dying was not legal anywhere in the U.S. Consequently, there were no data about who was using this option, or why. The authors were forced to conjecture, or, in the case of Wolf, to rely on data from the Netherlands, which Wolf acknowledged were not directly translatable for numerous reasons, including that while aid in dying was provided in the Netherlands, it was not technically legal. Even when Raymond, Battin, and Davis wrote in 1998 and 1999, aid in dying had not been legal in Oregon long enough for solid data to exist.

In the absence of reliable data, many – not only women but also members of other potentially vulnerable populations – had reason to fear that legal physician aid in dying would pose a danger to them. Today, however, nearly two decades of data from Oregon are easily available on the Oregon Health Authority's website showing that women do not constitute a disproportional number of aid in dying cases.[96] Although some opponents of legal aid in dying question the statistics, especially in regard to people living with disabilities, many who articulated genuine and thoughtful concerns about dangers to women and other vulnerable groups prior to the legalization of physician-assisted dying in

Oregon and other jurisdictions where medical aid in dying is legal may now be at least somewhat reassured that their worst fears were not realized.

Autonomy and Self-Directed Dying

Feminists are not the only authors to have written about self-directed dying. Since the 1990s hundreds of books and articles have been published arguing for or against physician aid in dying and euthanasia. Many focus on religion and explain why the author believes self-directed dying does or does not fit particular religious values. Others, especially those arguing in favor of medical aid in dying, present the stories of terminally ill suffering people as recalled by their family members or physicians. Still others support or oppose medical aid in dying from legal, philosophical, and ethical perspective. Although questions of autonomy are addressed implicitly or explicitly in these publications, two additional types of publications both broaden and deepen the examination of autonomy in self-directed dying. One type of literature questions the medical establishment's role in preventing hastened death. The other includes government reports and scholarly articles examining who uses medical aid in dying, and why, in the jurisdictions where it is legal.

To understand statistical reports and analytical reviews it is necessary to know what the law of each jurisdiction specifies about eligibility for aid, regulatory procedures, and reporting requirements. Although euthanasia had been widely practiced in the Netherlands for some time, the first jurisdiction to explicitly

legalize physician aid in dying was Oregon. The Oregon Death With Dignity Act, which came into effect in 1998, stipulated that the patient must: be 18 years of age or older and a resident of Oregon; be diagnosed by two physicians as having a terminal illness (defined as six months or less to live); be capable (defined as able to make and communicate health care decisions); make two oral requests to his or her physician, separated by at least 15 days, and one witnessed written request; be informed by the prescribing physician of feasible alternatives, including comfort care, hospice care and pain control; and self-administer any medication prescribed. The Act further stipulated that: the prescribing physician and a consulting physician must confirm the diagnosis and prognosis; if either physician believed the patient's decision might be influenced by a mental disorder, the patient must be referred for a mental health evaluation; the prescribing physician must request, but could not require, the patient to notify his or her next of kin of the request; and the physician must report the prescription for lethal medication to the Oregon Department of Human Services. In addition, pharmacies must report filling such prescriptions.

Annual statistics are easily available on the Oregon Health Department's website. From 1998 through the end of 2016, the latest year for which statistics are available, physicians wrote 1,749 prescriptions under the law and 1,127 people died from ingesting the prescribed drug.[97] Of these, 51.3 percent were male, 96.6 percent were white, and 72 percent had at least some college education.[98] The largest proportion, 45.4 percent, were married, while 23.4

percent were widowed and 23.3 percent were divorced.[99] Slightly over 90 percent were enrolled in hospice, only 1.4 percent were uninsured, and 94.0 percent died at home.[100] Most people, 77.2 percent, had cancer.[101] Losing autonomy was cited by 91.6 percent of patients as an end-of-life concern, making it the most frequently identified concern among those who hastened their own death.[102]

The Oregon Death with Dignity Act has become the model for other U.S. states legalizing aid in dying. Washington became the second state to legalize medical aid in dying. The Washington State Department of Health publishes an annual Death with Dignity report on its website. In 2016, medication was dispensed to 248 people, 192 of whom died after ingesting the medication.[103] Half of the people who hastened their own death were male, half were female.[104] As in Oregon, most had cancer, the vast majority were white, virtually all had health insurance, most had at least some college education, the largest proportion of people were married, more than 80 percent died at home, and more cited loss of autonomy as an end-of-life concern than any other.[105]

In Montana, medical aid in dying was legalized through a State Supreme Court decision that did not require the health department to track or publish medical aid in dying prescriptions or deaths. California, Vermont, and Colorado all require physicians to report aid in dying cases to their health departments, but aid in dying laws have not been in effect long enough in either California or

Colorado to gather annual data. In Vermont, data is not published, but statistics on the number of prescriptions written may be obtained upon request. [5]

Numerous authors reviewing the data from the states in which physician aid in dying is legal have concluded that there is little or no evidence of abuse of the system. Specifically, there is no credible evidence of individuals being coerced into hastening their own death. Similarly, the available statistics do not indicate that members of potentially vulnerable populations—including women, people of color, or poor people—are over-represented among those receiving aid in dying. In fact, individuals most likely to utilize aid in dying appear to have race, class, and, often, gender privilege. There is, therefore, no indication that legal physician aid in dying reduces the autonomy of members of vulnerable populations at the end of life.

Several authors have also pointed out, however, that U.S. laws fail to support the autonomy of some people who might want to, but cannot, access aid in dying. People with Amyotrophic Lateral Sclerosis (ALS), for example, are relatively likely, compared to people with other diagnoses, to consider obtaining aid in dying, but they face a special challenge. U.S. laws require that patients using aid in dying be able to administer the drug themselves, usually by drinking it. ALS, however, is a fatal neurodegenerative disease that robs patients of the ability to, for example, lift a glass to their lips and, eventually, even to swallow. In

[5] For example, in January of 2017, I submitted a request and was informed that 44 prescriptions had been written since legalization.

order to comply with the law, an ALS patient seeking aid in dying must be advanced enough in his or her disease that he or she is expected to die within six months, but not so advanced that he or she cannot self-administer medication. ALS patients who qualify to obtain a prescription may be forced to use it earlier than might otherwise have been the case simply in order to self-administer the medication while that is still possible.

Alzheimer's, too, is a neurodegenerative disease that confronts the patient with timing challenges in terms of complying with aid in dying laws. Alzheimer's patients do die, but they typically experience a protracted period of worsening dementia first. When they are first diagnosed, and might consider obtaining a prescription for future use, they are ineligible for aid because they are not expected to die within six months. By the time their death is imminent, they are not eligible because they are no longer of sound mind.

As will be explained in the last chapter, even patients who live in a state where aid in dying is legal and who qualify for aid in terms of age, residency, prognosis, and ability to self-administer medication may be unable to access aid. Access to participating physicians, especially for rural patients, and ability to pay for medication, especially for poor patients, can be significant barriers to accessing aid. Patients with psychiatric conditions may be excluded even if they have a terminal illness and can understand their options and communicate their wishes, and patients with progressive, debilitating, but non-fatal conditions such as Multiple Sclerosis (MS) are generally ineligible. Thus, even the most

progressive U.S. states, those that allow aid in dying for a subset of people, fail to support the autonomy of some individuals who might want, but who cannot access, aid.

U.S. right-to-die laws do less to support the autonomy of those who want to hasten their own death than do laws in the European countries that permit physician-assisted dying and euthanasia, as explained below. It is worth noting that these European countries – Holland, Belgium, Luxembourg, and Switzerland – might also be seen as doing more to promote the autonomy of those who do not want to hasten death and who instead want to continue to live as long as possible. Each of these countries has a more universal, affordable healthcare system, a broader social safety net, and a lower poverty rate than does the U.S. Medical care and social supports needed by the terminally ill, frail elderly, and people living with disabilities are less expensive and more widely available. These facts might mean that people seeking to hasten death in these countries could potentially be even less likely than people in the U.S. to feel pushed into death for financial reasons, out of loneliness and isolation, or to prevent them from burdening friends and family.

Regarding the right to die, in the Netherlands, euthanasia and physician aid in dying, although not technically legal, were practiced with increasing openness in the 1970s and 1980s. Dutch courts made a series of decisions that began to create case law that did not prosecute physicians providing aid in at least some circumstances, and in 1984 the Royal Dutch Medical Association

published guidelines describing how a physician could deal with, and perhaps comply with, a request for voluntary euthanasia with due care.[106] The Dutch Euthanasia Act, which came into effect in 2002, codified the practice of not prosecuting a physician who participated in euthanasia or physician aid in dying so long as he or she acted in accordance with criteria for due care. These criteria required that the physician be convinced that the request was voluntary and well-considered, believed that the patient was experiencing unbearable and hopeless suffering, had provided the patient with complete information about the medical condition and treatment options, had concluded with the patient that there was no reasonable alternative, had consulted with at least one other physician independent of the case who had seen the patient and provided a written opinion with respect to the above, and had carried out the life-ending intervention in a medically correct way.[107] Physicians engaging in euthanasia or assisted dying were required to report the case to a Euthanasia Review Committee, of which there was one for each of the five health jurisdictions in the Netherlands. Each Euthanasia Review Committee consisted of three members: a physician, a lawyer, and an ethicist. Euthanasia Review Committees were charged with reviewing all cases of euthanasia and assisted dying and referring to prosecutors any that did not comply with due care criteria.

In many ways the Dutch system does much more than the U.S. system to support personal autonomy for individuals wishing to hasten their own death. While the prescribing physician must be convinced that the patient is suffering

unbearably, the patient need not be terminally ill. In 2015, physicians reported 5,516 cases of aid in dying and euthanasia, representing 3.9 percent of all deaths in the Netherlands. Cancer was the most common underlying condition, followed by cardiopulmonary diseases and neurodegenerative diseases. Dementia was present in 2 percent of cases, and untreatable mental illness was present in 1 percent.[108] Of the 5,516 cases examined by Euthanasia Review Committees, four were judged to have not met due care criteria, indicating a 0.07 percent rate of noncompliance and 99.93 percent rate of compliance with the law.[109]

Because doctors in the Netherlands can administer medication, patients with ALS do not have to time their death such that they are still able to self-administer the medication. And because terminal illness is not a requirement, patients with MS can receive aid if they desire it. Competent patients in the early stages of dementia may receive aid, but dementia patients may also receive aid when their disease has progressed, so long as they made the request in writing while they were competent. And, rather than being excluded for psychiatric reasons, patients suffering from untreatable depression and other mental illnesses may receive assistance if the physician is convinced that their condition is hopeless. Terminally ill children 12 and older may also receive aid in some circumstances. Patients who are denied aid by their regular doctor, often on the basis of religious or moral grounds, may apply to an End of Life Clinic that provides mobile services for patients who could not otherwise access assistance,

and they may obtain aid if they are judged to meet the criteria laid out in the law. In 2010 a Citizen's Initiative named Out of Free Will campaigned to ensure that any person age 70 or older could receive assistance, regardless of his or her reason. The campaign garnered numerous signatures but did not result in any change in the law.

In Belgium, as in the Netherlands, euthanasia and assisted dying were legalized in 2002, making Belgium the second country to pass an explicit law permitting and regulating medical aid in dying. The language of the Belgian law was similar to the language of the Dutch law; it required unbearable and incurable suffering, consultation with other physicians, and reporting to a government agency. The doctor involved must be present at the death. In 2014, Belgium became the first and, to date, only jurisdiction to remove age restrictions from eligibility criteria in cases of terminal illness. In recent years the country has been the focus of several media reports about non-terminally ill patients requesting, and receiving, a hastened death on the basis of psychiatric and psychological concerns alone.[110]

Luxembourg legalized euthanasia and assisted dying in 2009, becoming the third country to do so. As one of the three Benelux states, it passed legislation very similar to that passed in the Netherlands and Belgium in 2002. The Grand Duke of Luxembourg, a devout Catholic, refused to sign the law in 2008, but Luxembourg amended its Constitution to allow for a bypass of his signature, and the law came into effect in 2009. Each year, approximately seven

of the county's roughly 500,000 inhabitants die an assisted death.[111] Luxembourg has a euthanasia review commission that releases semi-annual reports, which have consistently concluded that abuse of the law has not taken place.[112]

Compared to Luxembourg, Belgium, and the Netherlands, Switzerland, where medical aid in dying is permitted, has developed legally in a very different way. In 1918, a government comment on the Swiss penal code noted that suicide was not a crime, that assisting suicide could be done for altruistic reasons, and that assisting suicide should be a crime only if done for selfish motives.[113] Article 115 of the Swiss Penal Code, in effect since 1942, clarified that people who assisted a suicide for altruistic rather than selfish motives would not be prosecuted.[114] Euthanasia, however, is not legal; Swiss physicians may not administer drugs for the purpose of hastening death. Physicians are involved, nonetheless, because to obtain drugs, the patient must see a physician who writes a prescription to be filled at a pharmacy. The patient must be able to self-administer the medication. Typically, Swiss doctors are not present at the death unless they are there in a personal, rather than a professional, capacity. Assisted deaths usually occur on the premises of one of several assisted death organizations and are routinely reported to the authorities. A notable feature of the Swiss law is that it allows people from other countries to visit suicide assistance organizations to receive aid. Dubbed "suicide tourism," this possibility increases the autonomy of individuals seeking to hasten death who live in jurisdictions where legal aid in dying is not available from physicians. The ability

to exercise this autonomy, however, is dependent upon one having the financial means and the physical ability to travel to Switzerland to obtain the desired aid.

In 2016, Canada became the latest country to legalize medical aid in dying. In 2014 the National Assembly in Quebec passed Bill 52, the "Death with Dignity Law," which took effect at the end of 2015 in that province. On February 6, 2015, however, the Supreme Court of Canada ruled in *Carter v Canada* that prohibiting aid in dying in any Canadian province violated the Canadian Charter of Rights and Freedoms.[115] The Court specified that aid in dying should not be criminal when provided to a resident adult with a grievous and irremediable medical condition that caused enduring suffering intolerable to the individual.[116] It gave the federal government one year to develop appropriate guidelines, a deadline that was later pushed back six months. The Canadian Ministry of Justice and Health established an External Panel on Options for a Legislative Response to *Carter v. Canada*. The panel was composed of three distinguished professionals: Dr. Harvey Max Chochinov, an expert in psychiatry and palliative care; Professor Benoit Pelletier, a lawyer and academician; and Professor Catherine Frazee, a long-time disability rights activist and former Chief Commissioner of the Ontario Human Rights Commission.[117] Both Dr. Chochinov and Professor Frazee were on record as opposing legal aid in dying, but Frazee reported to the *Huffington Post* that all three panel members were committed to "having respectful and open discussion with Canadians . . ."[118] The panel obtained input from individuals and organizations as well as from experts in

countries where medical aid in dying was already legal. It published *Consultations on Physician-Assisted Dying – A Summary of Results and Key Findings,* which, among other things, reviewed aid-in-dying criteria in other countries and noted that nothing in the *Carter v Canada* required that people be terminally ill to receive aid.[119] Despite this, on June 17, 2016, Canada's Parliament passed an aid-in-dying bill requiring that aid be limited to people whose natural death was reasonably foreseeable or incurable.[120] It required waiting periods and the involvement of more than one physician, and it did not provide for aid to non-residents or through advance directives, stating that individuals must be capable of providing informed consent at the time the aid is provided. It did allow for both self-administration of life-ending drugs as well as administration of such drugs by a doctor or nurse practitioner.[121] The bill was much more restrictive than the Supreme Court of Canada required, meaning that people who might have been interpreted as being eligible for aid after the *Carter v Canada* decision may have later found themselves unable to access assistance. Canada's legal aid-in-dying laws have not been in effect long enough for annual statistics to be available. Preliminary data indicate that, between June 17 and December 31, 2016, 803 Canadians died an assisted death; the average patient was 77 years old, the most commonly cited underlying condition was cancer, and the percentages by gender were 49 percent male, 51 percent female, which is consistent with the gender ratio of Canadians in the general population in that age range.[122]

As noted above, numerous studies of assisted death statistics in the jurisdictions where it is legal and data are available document the great extent to which laws are followed, showing no evidence of a "slippery slope." In 2013, for example, in the *Journal of Law, Medicine & Ethics'* special issue on human rights and disability, Penney Lewis and Isra Black published their article, "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon, and Switzerland." They concluded that the evidence suggested that individuals who received assisted dying in these four jurisdictions made valid requests and that those who provided assistances did so lawfully.[123] In the same year, Nicole Steck and her colleagues published their article, "Euthanasia and Assisted Suicide in Selected European Countries and US States: Systematic Literature Review," in *Medical Care,* the official journal of the Medical Care Section of the American Public Health Association. They reported that, worldwide, the typical person dying a legal assisted death was a well-educated male cancer patient between 60 and 85 years of age.[124] They noted variations by jurisdiction, however, and the following year Steck and her associates published a different article in the *International Journal of Epidemiology.* This article, "Suicide Assisted by Right to Die Associations: A Population-Based Cohort Study," examined epidemiological trends in Switzerland to discover whether members of potentially vulnerable or disadvantaged groups in that country might be more likely to die with medical aid than other people. They determined that in Switzerland dying an assisted death

was associated with being female and with situations that might indicate greater vulnerability, such as living alone or being divorced, but also with higher education and socio-economic status.[125] They noted, “The higher rates among the better educated and those living in neighborhoods of higher socio-economic standing does not support the ‘slippery slope’ argument but might reflect inequities in access to assisted suicide.”[126]

“Slippery slope” arguments refer to the concern that, once aid in dying is legalized and normalized, members of vulnerable populations will experience decreased autonomy as they are pushed, consciously or unconsciously, covertly or overtly, toward requesting or accepting assisted dying. The existing literature documents no credible evidence to support “slippery slope” fears. When aid in dying is legalized and becomes more available, reports show that, over time, larger numbers of people in a given jurisdiction request and receive it.[127] In *Ending Life: Ethics and the Way We Die,* Margaret Battin suggests that our current point of view about personal autonomy in death and dying is unduly limited. She suggests that at present even the mainstream right-to-die movement views physician-assisted dying as something that should be a rare last resort, but argues that if “the culture-wide view about choicemaking in death and dying were more fully held *sub specie aeternitatis. . .* self-directed dying would be the norm, though of course different people would direct their deaths in quite different ways."[128]

Numerous researchers have collected and analyzed data that document no evidence of a “slippery slope” toward vulnerable people’s rights being abused as a result of legalized aid in dying. Pam Oliver, on the other hand, stands out because of her work documenting the ways that people seeking aid in dying are often poorly served or denied their rights even where aid in dying is legal. In *Addressing Access Barriers to Legal Assisted Dying,* a formative evaluation analysis of barriers and facilitative factors affecting people seeking aid in dying in the US, Quebec, and Europe, she documents how existing statutory and institutional rules can sometimes frustrate the intentions of people seeking to hasten death. She identifies as access barriers policies about self-administering medication, excessive mandatory waiting periods, terminal illness criteria, mental health consultation requirements, costs, along with lack of infrastructure, clinician education and lack of participating physician availability.[129] While Oliver firmly supports regulatory safeguards, her work clearly demonstrates that many of the safeguards included in current laws may not only be ineffective in protecting vulnerable individuals but can also reduce the self-direction and autonomy of individuals seeking aid in dying.

Consideration of the policies and epidemiology of assisted dying worldwide may go some distance toward reassuring those who worried that legal aid in dying would oppress members of vulnerable populations, including women. Below is a selection of a different type of literature: publications commenting on

how the U.S. medical establishment suppresses the autonomy of individuals seeking to hasten death, including, but not limited to, the terminally ill.

In their 1999 book *Come Lovely and Soothing Death: The Right to Die Movement in the United States*, one of the few books about the history of the right-to-die movement, sociologists Elaine Fox, Jeffrey Kamakahi, and Stella Čapek assert that the right-to-die movement challenges the medical model. Specifically, they cite what French social philosopher Michel Foucault calls the "power/knowledge" model and describe how the medical establishment has "wedged itself in as the primary gatekeeper (middleman) between the population at large and medical services" through its "exclusive claim to medical knowledge."[130] They propose an alternative model that they call "power/freedom," in which "access to information, technology and other resources can be wrested from power/knowledge groups and institutions and given to individuals."[131] These authors conclude that the right-to-die movement asks, "Whose life is it, anyway?" and "demanded empowerment of individuals and communities."[132]

The authors' conclusion that the right-to-die movement challenges the hegemony of the medical establishment may have been true when they were writing, before the Oregon Death with Dignity Act was well established and when many possible scenarios regarding self-directed dying were still being discussed in the U.S. The way the right-to-die movement has developed since the 1990s, however, can be viewed as having increased, rather than decreased, the medicalization of self-directed dying.

Case law, professional standards of care, risk management practices and institutional polices seem in most cases to combine to compel professionals coming into contact with potentially suicidal individuals to prevent the suicide, even when the person is mentally competent and terminally ill.[6] Mental health care professionals, in particular, are urged to take preventive action up to and including incarcerating people against their will in psychiatric facilities, lest these professionals suffer the professional, economic, or legal consequences of allowing a patient to end her life. A few psychiatrists and psychologists, however, do assert that individuals have a right to commit suicide and that mental health care professionals should refrain from taking coercive action to prevent suicide in at least some circumstances.[133]

In his book *Rational Suicide? Implications for Mental Health Professionals*, also written in the 1990s, Dr. James Werth describes guidelines for practice that could be adopted by care providers who accept what he calls “rational suicide.” His suggested criteria include the following:

1. The person considering suicide has an unremitting “hopeless” condition. “Hopeless” conditions include, but are not necessarily limited to, terminal illnesses, severe physical and/or psychological pain, physically or mentally debilitating and/or deteriorating conditions, or quality of life no longer acceptable to the individual.

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[6] When I trained as an in-home hospice volunteer for Bozeman Deaconess Hospital, I was instructed to take note of whether a dying patient might be hoarding medication, and, if so, to report it to hospice staff so that they could take action to prevent a potential suicide.

2. The person makes the choice as a free agent (i.e., is not pressured by others to choose suicide).

3. The person has engaged in a sound decision-making process. This process should include the following:
    a) Consultation with a mental health professional who can make an assessment of mental competence (which would include an absence of treatable major depression);
    b) Non-impulsive consideration of all alternatives;
    c) Consideration of the congruence of the act with one's personal values;
    d) Consideration of the impact on significant others;
    e) Consultation with objective others (e.g., medical and religious professionals) and with significant others.[134]

In his article, "Using Rational Suicide as an Intervention in Preventing Irrational Suicide," Werth argues that a standard of care that requires the rejection of suicide may serve some clients poorly. Instead, he says, "Accepting the possibility that hastening death through suicide can be the best option for someone allows for the opportunity to intervene with some clients who would be resistant to purely preventive efforts…"[135] "Using the set of criteria for rational suicide from the literature," he continues, "provides an organizing framework for discussions that will allow for the review of relevant factors that will help the clinician and client determine whether suicide is indeed the best option.[136]

Ideally, the client enters into the therapeutic relationship voluntarily and with a commitment not to carry out a plan to kill himself or herself without undertaking the discussion necessary to assure the clinician that the decision is rational. Werth and his co-author James Rogers address the issue in their article, "Assessing for Impaired Judgment as a Means of Meeting the 'Duty to Protect' when a Client is a Potential Harm-to-Self: Implications for Clients making End-of-

Life Decisions." They suggest that the standard for whether or not to intervene should be whether or not the client's judgment is impaired. They write, "If a person's ability to make judgments about various decisions is not impaired, then we do not believe that the counselor has the obligation, or the right, to interfere with the individual following through with a given decision, even if the result is death."[137]

Werth's suggestions have not been promoted by the American Psychological Association (APA) or by schools training new mental health professionals. Although the APA takes no position on physician-assisted dying, it does educate members about case law and risk management. Regarding case law, in his article, "Mental Health Professionals and Assisted Death: Perceived Ethical Obligations and Proposed Guidelines for Practice," Werth states, "It is widely assumed among mental health professionals that there is a legal obligation to attempt to prevent a client from harming himself or herself."[138]

Noting that suicide prevention has become an industry managed by the state and by the medical and public health establishments, controversial psychiatrist and anti-psychiatry critic Dr. Thomas Szasz points out that the state has often used its power to kill when it sees fit, whether through capital punishment, war, or other methods. He writes, "What the Authorities abhor is letting people kill themselves, correctly recognizing in that act the individual's revolt against authority, and his assertion of autonomy."[139] He points out that, while suicide is technically legal, its legality is highly unusual in that someone

attempting to commit this legal act may be involuntarily incarcerated to prevent commission of the legal act, and that anyone who assists in committing this legal act is almost always considered a criminal.[140] He further states, “One of the most important differences between free and totalitarian countries is that people can leave the former without permission by authorities of the State, but they can leave the later only with their explicit authorization.”[141]

Susan Wolf notes in her article, “Physician-Assisted Suicide, Abortion, and Treatment Refusal: Using Gender to Analyze the Difference,” that although suicide has been decriminalized, there is no right to suicide. She writes, “ . . . a person attempting suicide may not only be stopped, she may be committed to a mental health facility for evaluation.” [142]

In her book, *Rational Suicide, Irrational Laws: Examining Current Approaches to Suicide in Policy and Law,* Susan Stefan argues that involuntary commitment is not an effective tool for preventing suicide and may even exacerbate suicidality.[143] She suggests that if we vastly limited the conditions under which suicidal individuals could be involuntarily committed, fewer people would die, because more people would be able to talk openly about their suicidal ideations without fear of losing their civil rights.[144] With the exception of people who are, for example, drunk, hearing angry voices commanding them to kill themselves, extremely impulsive, or otherwise unable to understand and control what they are doing—whom she believes should be “held safe, for a very short period of time, whether they want it or not”—individuals considering hastening

their own death should not be involuntarily committed or otherwise controlled by mental health professionals.[145] She further suggests that mental health care professionals should not be expected to control the actions of their patients and should not be held liable to the extent that they are today when patients commit suicide.[146] She quotes Sean Donovan, who runs a group for people who are suicidal and has been suicidal himself as saying, “What we’ve found is that by letting go of this need to control, ultimately, whether someone lives or dies that many more people find the wisdom and strength within themselves to live, and on their own terms.”[147]

Stefan is not necessarily an advocate of physician aid in dying. For her, whether and how someone should be *prevented from* hastening death, and whether and how they should be *assisted in* hastening death, seem to be very different questions. She argues that, if aid in dying for terminally ill people is to be available, drugs should be provided by non-physicians, such as other hospice personnel. In spite of the fact that she is opposed to allowing doctors to administer lethal medications to terminally ill patients and rejects active aid in dying for people who are not terminally ill, she is a strong advocate for the rights of people considering hastening death. In her book section, “Neither Autonomy nor Paternalism: A Third Way,” Stefan urges readers to consider the upstream causes of individuals’ desire to hasten death and to find ways to actually improve the quality of people’s lives rather than simply prevent their deaths.[148] Perhaps Stefan’s greatest contribution to the debate about aid in dying is her development

of a “unified field theory” of suicide. Unlike right-to-die advocates who insist that a terminally ill person hastening death is not committing suicide, Stefan does not shy away from the term “suicide,” acknowledges that there are many reasons one might want to hasten death, understands that some people will, indeed, die by their own hand, and offers constructive suggestions about how to improve the quality of life and the quality of care for people all along the continuum in their considerations of death and the value of life.[149]

While Stefan opposes active assistance in dying for people whose underlying complaint is mental illness, Elena Lindemans examines the consequences of denying aid to individuals living with intractable depression and anxiety. In her documentary video *Mothers Don’t Jump from Buildings,* Lindemans, whose mother committed suicide by jumping off a tall residential building after repeatedly being denied euthanasia in the Netherlands, interviews the physicians who treated her mother but denied her aid in dying, residents of the building from which her mother jumped, and family members who had spent years caring for her mother. The video documents the trauma to the patient and the survivors when a person who has firmly settled on suicide as a solution to her life’s problems cannot attain death through peaceful methods and must resort to violent means. This deeply moving personal account raises questions about the harms and benefits to individuals and society of denying medical aid in dying requested on the grounds of mental anguish.[150]

In her book, *Leaving You: The Cultural Meaning of Suicide,* Lisa Lieberman explores our society's reasons for patronizing and treating individuals who want to die as children in need of protection.[151] She describes suicide as an expression of autonomy that threatens the foundations of public authority. "To opt out of a system is effectively to condemn it," she writes, pointing out that "even the most oppressed members of society have the power to challenge its assumptions by voluntarily removing themselves from the community."[152] "As a political statement," she continues, "the act denotes dissatisfaction with the present and repudiation of hope in the future: a negation of the liberal promise on which modern democracies are founded."[153]

In his introduction to *History of Suicide: Voluntary Death in Western Culture,* Georges Minois writes, "Humanity has existed thus far because humans have found sufficient reason to remain alive, but nevertheless a certain number of individuals decide that life is no longer worth living and prefer to depart voluntarily before being sent on their way by illness, old age, or war."[154] "Some think them mad," he says.[155] But, he continues, "Cato, Seneca, Henry de Montherlant, Bruno Bettelheim, and many others have regarded the specifically human act of voluntary death as the supreme proof of liberty, of the freedom to decide one's own being or nonbeing."[156]

Szasz writes, "In principle, killing oneself is not different from other acts that have far-reaching, irreversible consequences, such as begetting a child."[157] "Practicing birth control and practicing death control as well as abstaining from

these practices," he says, "have far-reaching consequences, both for the individual and for others."[158] "Birth control," he continues, "is an issue for the young; death control, for the old."[159] "We are not responsible for being born," he writes."[160] "We are born involuntarily."[161] "But from the moment we acquire the power of self-reflection, we are, increasingly as we age, responsible for how we live and how we die."[162]

Regarding the personalities of individuals who seek to hasten their own death in jurisdictions where aid in dying is legal, Oliver reports that family accounts of people seeking aid portray them as "highly autonomous people who plan for the future, do not fear death *per se,* have clear ideas about what is and is not acceptable to them, and are sceptical about the value to them of palliative care and practitioners in that area."[163] She cites the findings of Helene Stark and associates showing that factors motivating a wish for assisted dying are not primarily physical pain or suffering but rather "existential suffering . . . related to an aggregate experience of multiple, interdependent losses in physical, psychological, [and] social functioning" leading to actual or anticipated loss of, among other things, ". . . personal autonomy, control over one's own decisions, sense of community, and sense of self and identity."[164]

While Oliver strongly supports self-direction at the end of life, her report does not place a value, positive or negative, on an individual's decision to hasten (or not to hasten) death. A different author, Karolynn Siegel, in her argument against legal aid in dying, however, casts a desire for self-direction at the end of

life and a decision to hasten death as a personality flaw. In *Psychosocial Aspects of Rational Suicide*, Siegel writes about people who want to see "suicide as a nonpathological option to life":

> Many of them derive a feeling of comfort from the knowledge that they will determine the time and circumstances of their death. A sense of controlling exactly how and when they will die appeals to the omnipotent strivings of these individuals."[165]

She goes on to say, "Another quality frequently observed in those who demand their right-to-die is an inability to tolerate uncertainty in life, such as is introduced by a serious illness. The need to control death is an attempt to control the anxiety associated with such uncertainty."[166] She continues, ". . . their own need to idealize and transfigure the experience of death into a creative act appears to be a defense against underlying feelings of helplessness and dread of death."[167] Siegel states:

> Finally, it is important to remember that psychodynamic investigation into the motivation of suicidal individuals reveals that they are not pursuing a predominantly rational act to attain rational ends, even when executed by individuals who appear notably rational. Rather, it is a magical act intended to achieve an irrational, delusional and deceptive end.[168]

She concludes that ". . . it is imperative not to further erode the negative social sanctions attached to suicide."[1697]

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[7] These quotes remind me of nothing so much as Betty Friedan's descriptions in *The Feminine Mystique* of how mental health professional in mid-20th century American pathologized the desires of middle-class housewives to have more in their lives than matrimony and motherhood, and of Anne Koedt's description in

Siegel views an individual's desire to exert control over the experience of one's own dying as pathological. Dr. Sherwin Nuland, in his book, *How We Die: Reflections of Life's Final Chapter,* however, critiques physicians' desire to control the deaths of others. Whether one is attempting to control one's own death experience, or the death experience of another, is an important distinction. The issue of control, and the question of who gets to have control, is often key. As right-to-die advocates point out, while a sizeable minority of dying people who obtain lethal prescriptions don't actually take the drugs, they report a better quality of life simply knowing that they can hasten death if they wish to, that they can be in control.[170] For some people, simply knowing that they have the ability to control the circumstances of their death may make their quality of life, and of their dying, better.[171]

Siegel, like many mental health professionals, may see the desire to hasten one's own death as *ipso facto* evidence of mental illness. Others disagree. Viktor Frankl, Holocaust survivor and author of *The Unheard Cry for Meaning: Psychotherapy and Humanism*, among many other books, says:

> Sigmund Freud, it is true, once wrote 'The moment one inquires about the sense or value of life, one is sick:' but I rather think that one thereby manifests one's humanness. It is a human achievement to quest for a meaning to life, and even to question whether such a meaning is available at all."[172]

"The Myth of the Vaginal Orgasm" of how psychiatrists pathologized as infantile women who had orgasms as a result of clitoral, rather than only vaginal, stimulation.

Similarly, James Hillman, author of multiple influential books including *Suicide and the Soul,* writes, “Until we can choose death, we cannot choose life. Until we can say no to life, we have not really said yes to it, but have only been carried along by its collective stream.”[173]

In summary, six U.S. states, Canada, and four European countries, have instituted laws that allow aid in dying in at least some circumstances. These laws do or do not support individual autonomy in various ways. European policies are significantly more permissive than are U.S. aid in dying laws. [174] Not one of these four European countries requires that a person seeking assistance in dying be terminally ill. These European countries also provide a much broader medical, social, and economic safety net for all, including people considering hastening death. In Belgium there are no age restrictions on receiving aid, and in the Netherlands children over the age of 12 may receive aid in some circumstances. In most countries people are eligible for aid even if they have a psychiatric diagnosis, so long as they are able to understand, make, and communicate healthcare decisions. In some countries, people with early Alzheimer’s and other forms of progressive dementia can create advanced directives regarding aid in dying that will be honored in the future. In most countries, physicians may actively administer a lethal dose of medication. In Switzerland, one need not be a resident to obtain aid. And in Switzerland, assistance need not be provided by a physician. In the absence of evidence that European aid in dying laws result in any lessoning of autonomy for members of vulnerable populations, in light of the

fact that European countries offer a large social safety net, and considering the fact that larger proportions of the population can and do elect assisted dying in Europe than in the U.S., one might reasonably conclude that European laws do more to support autonomy at the end of life for those who want to hasten death than do American laws.

As noted above, however, committing suicide is not a crime in any state in the U.S. One might wonder, then, why there is any perceived need for a right-to-die movement. After all, it is certain that each of us will die eventually. If we want to hasten death, most of us can choose from a range of options such as shooting ourselves, hanging ourselves, jumping off tall buildings, throwing ourselves in front of approaching trains, driving into bridge abutments, or any number of other violent options. Of course, none of these options are peaceful for those wishing to hasten death or pleasant for those who must deal with the remains, and most are out of the reach of weak, bedridden, terminally ill patients at the very end of their lives.

Death, like birth, used to occur primarily at home and now occurs primarily in the hospital, but poll after poll shows that the majority of Americans say they want to die at home surrounded by loved ones. Theoretically, if any of these people wanted to hasten their own death, and assuming they had the necessary equipment and physical strength, there would be nothing to prevent them from hanging or shooting themselves as their loved ones gathered around. Most people, however, would prefer more peaceful, non-mutilating options. Not being

able to access “peaceful pills” reduces the autonomy of those wanting to bring about a peaceful, reliable, self-directed death.

Most states have statutes explicitly outlawing assisting suicide, whether the person providing assistance is a physician or a lay person.[175] In other states, an individual who provides aid can be charged with manslaughter or even murder.[176] Although the definition of “providing aid” is not always clear, writing a prescription for a lethal dose of medication, assisting another in purchasing such medication over the internet or in another country, or even lifting a dose of medication to the person’s mouth may all be judged “providing aid.”

As mentioned above, the APA takes no position for or against physician-assisted dying. The American Medical Student Association, the American Medical Women’s Association, and the American Public Health Association stand out as being among the relatively few organizational proponents of legal physician aid in dying. Virtually all other mainstream health-related professional associations either take no position on physician-assisted dying or, like the American Medical Association, actively oppose it.[8]

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[8] To my knowledge, no mainstream U.S. health-related professional association has published a position statement on any form of self-directed dying other than the Oregon model, which permits aid to be provided by physicians to terminally ill, mentally competent adult patients who meet strict criteria. In general, as Davis points out, suicide is almost always written about in the literature as a risk to be reduced or an outcome to be prevented.

To support greater autonomy in self-directed dying, numerous U.S. policies would need to be changed. If the U.S. were to adopt the most permissive policies modeled by other countries and suggested by authors cited above, we would then have a situation in which:

- Assisting someone in committing suicide would not be a crime unless assistance was provided for selfish rather than altruistic reasons;
- Adults would not need to be terminally ill to receive aid;
- Physicians would be able to provide prescriptions to be self-administered by patients and would also be able to administer medication directly, at least to patients unable to self-administer due to a physical inability;
- People preferring to receive aid not from physicians but instead from non-medical organizations or friends or family members would be able to do so;
- People considering ending their lives would be able, if they so chose, to honestly discuss their thoughts with mental health professionals with little reason to fear that their privacy, autonomy, liberty, or civil rights would be violated;
- Patients in the early phases of dementia would be able to create advanced directives that would allow them to receive a lethal dose of medication after their dementia had progressed;

- Children of any age would be able to receive aid if they were terminally ill so long as they could demonstrate that they could understand their options and communicate their decision and their parents and doctors agreed;
- Patients with psychiatric diagnoses would be able to obtain aid so long as they were able to understand their options and communicate their decision.

For all this to happen, we as a society would have to move beyond what Davis calls the "comforting belief that life is always worth living." [177] Simultaneously, we would have to reject the taboo against suicide. We would need to temper our belief that prolonging life is always good and consider the idea that hastening death is not always bad. We would need to embrace the idea that, in many cases, as Dr. Battin suggests, dying is something we can actively *do*, and that how we do it is at least as important as how we have done everything else in our lives.

To support this vision, a number of policy changes would be needed. An abbreviated list of these includes:

- Repealing statutes that criminalize assisting at least some suicides;
- Empowering physicians to prescribe and administer lethal doses of medication;
- Revising health care curricula regarding suicide;

- Establishing case law that protects care providers whose patients elect suicide;
- Eliminating health-related professional association positions that oppose self-directed dying;
- Refining advice given by risk managers and malpractice insurers whose clients are health care professionals;
- Altering clauses in life insurance policies that entitle companies to refuse to make payment if death results from suicide.

Ideally we would also, among other things:

- Institute universal health care;
- Expand the social safety net, including but not limited to practical and social supports for the ill, frail elderly, and disabled.

We might even reconsider whether, and how, to change restrictions on controlled substances to increase people's access to drugs that reliably produce a peaceful death.

[40] Jean Grimshaw, "Autonomy and Identity in Feminist Thinking," in *Feminist Theory: A Philosophical Anthology*, ed. Ann E. Cudd and Robin O. Andreasen (Malden: Blackwell Publishing Ltd., 2005), 329.

[41] Regarding what Tong describes as feminine ethics, she draws heavily on Carol Gilligan's *In a Different Voice: Psychological Theory and Women's Development,* and on Nel Nodding's *Caring: A Feminine Approach to Ethics and Moral Education*. Regarding what she describes as feminist ethics, Tong draws on multiple authors including Alison Jaggar, especially her 1992 article "Feminist Ethics."

[42] Rosemarie Tong, *Feminine and Feminist Ethics* (Belmont: Wadsworth Publishing Company, 1993), 49.

[43] Ibid., 50.

[44] Ibid.

[45] Ibid.

[46] Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Cambridge: Harvard University Press, 1982).

[47] Harvard University Press, http://www.hup.harvard.edu/catalog.php?isbn=9780674970960.

[48] Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley: University of California Press, 1984).

[49] Amy Allen, *The Politics of Ourselves: Power, Autonomy, and Gender in Contemporary Critical Theory* (New York: Columbia University Press, 2008), 5.

[50] Williams, *Truth, Autonomy, and Speech: Feminist Theory and the First Amendment*, 71.

[51] Ibid.

[52] Ibid., 148.

[53] Ibid., 150.

[54] Leslie Bender, "A Feminist Analysis of Physician-Assisted Dying and Voluntary Active Euthanasia," *Tennessee Law Review*, no. 59 (1992).

[55] Sydney Callahan, "A Feminist Case against Euthanasia: Women Should Be Especially Wary of Arguments for 'the Freedom to Die'," https://www.chausa.org/docs/default-source/health-progress/a-feminist-case-against-euthanasia-pdf.pdf?sfvrsn=0.

[56] Downie and Sherwin, "A Feminist Exploration of Issues around Assisted Death."

[57] Wolf, "Gender, Feminism and Death: Physician-Asisted Suicide and Euthanasia," 306.

[58] Ibid.

[59] Susan Wolf, "Physician-Assisted Suicide, Abortion, and Treatment Refusal; Using Gender to Analyze the Difference," in *Physician-Assisted Suicide*, ed. Robert Weir (Bloomington: Indiana University Press, 1997), 167-201.

[60] Ibid., 174.

[61] Ibid.

[62] Ibid.

[63] Margaret Pabst Battin, "Physician-Assisted Suicide: Safe, Legal, Rare?," in *Physician-Assisted Suicide: Expandin the Debate* (New York: Routeledge, 1998), 64.

[64] Ibid., 66-67.

[65] Dena Davis, "Why Suicide Is Like Contraception: A Women-Centered View," in *Physician-Assisted Suicide: Expanding the Debate*, ed. Margaret Battin, Rhodes, Rosamond, and Silvers, Anita (New York: Routeledge, 1998), 114.

[66] Ibid., 119.

[67] Ibid.

[68] Ibid.

[69] Ibid., 118.

[70] Ibid., 115.

[71] Diane Raymond, ""Fatal Practices": A Feminist Analysis of Physician-Assisted Suicide and Euthanasia," *Hypatia* 14, no. 2 (1999): 21.

[72] Downie and Sherwin, "A Feminist Exploration of Issues around Assisted Death," 326.

[73] Bender, "A Feminist Analysis of Physician-Assisted Dying and Voluntary Active Euthanasia," 536.

[74] Ibid.

[75] Ibid.

[76] Ibid.

[77] Downie and Sherwin, "A Feminist Exploration of Issues around Assisted Death," 327.

[78] Ibid.

[79] Ibid., 329.

[80] Ibid., 314.

[81] Ibid., 315.

[82] Ibid.

[83] Ibid., 325.

[84] Bender, "A Feminist Analysis of Physician-Assisted Dying and Voluntary Active Euthanasia," 522.

[85] Davis, "Why Suicide Is Like Contraception: A Women-Centered View," 117.

[86] Ibid.

[87] Ibid., 118.

[88] Ibid.

[89] Ibid.

[90] Rebecca Dresser, "What Bioethics Can Learn from the Women's Health Movement," in *Feminism and Bioethics: Beyond Reproduction*, ed. Susan Wolf (New York: Oxford University Press, 1996), 146.

[91] Ibid., 152.

[92] Ibid.

[93] Ibid., 151.

[94] Ibid., 151-52.

[95] Ibid., 152.

[96]Oregon Health Authority, "Death with Dignity Act" https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf.

[97] Ibid.

[98] Ibid.

[99] Ibid.

[100] Ibid.

[101] Ibid.

[102] Ibid.

[103] Washington State Department of Health, "Washington State Death with Dignity Act Report 2016," http://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2016.pdf.

[104] U.S. Census Bureau, "65+ in the United States: 2010."

[105] Ibid.

[106] J. A. Rietjens et al., "Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?," *J Bioeth Inq* 6, no. 3 (2009).

[107] G. K. Kimsma, "Death by Request in the Netherlands: Facts, the Legal Context and Effects on Physicians, Patients and Families," *Med Health Care Philos* 13, no. 4 (2010): 356.

[108] Neil Francis, "Netherlands - 2015 Euthanasia Report Card," http://www.dyingforchoice.com/resources/fact-files/netherlands-2015-euthanasia-report-card. Ben Brumfield, "Dutch Ethanasia Clinic Offers Mobile Services," *CNN*, March 9 2012.

[109] Francis, "Netherlands - 2015 Euthanasia Report Card".

[110] For example, see Rachel Avive, "The Death Treatment: When Should People with a Non-Terminal Illness Be Helped to Die?," The New Yorker, http://www.newyorker.com/magazine/2015/06/22/the-death-treatment.

[111] Alex Schadenberg, "Luxembourg Euthanasia Report," http://alexschadenberg.blogspot.com/2015/04/luxembourg-euthanasia-report.html.

[112] Luxemburger Wort, "Luxembourg Euthanasia Report Finds No Abuses of the Law," *Luxemburger Wort*, April 22, 2015, http://www.wort.lu/en/politics/15-cases-in-2013-and-14-luxembourg-euthanasia-report-finds-no-abuses-of-the-law-5537989d0c88b46a8ce57d97.

[113] S. A. Hurst and A. Mauron, "Assisted Suicide and Euthanasia in Switzerland: Allowing a Role for Non-Physicians," *BMJ* 326, no. 7383 (2003): 271.

[114] Susan Stefan, *Rational Suicide, Irrational Laws: Examining Current Approaches to Suicide in Policy and Law* (New York: Oxford University Press, 2016), 187.

[115] Dying With Dignity Canada, "Carter V Canada and the Road to Choice," http://www.dyingwithdignity.ca/carter_v_canada_and_the_road_to_choice.

[116] Ibid.

[117] Government of Canada Department of Justice, "Consultations on Physician-Assisted Dying - Summary of Results and Key Findings," http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/p2.html.

[118] Althia Raj, "Catherine Frazee Says Her Assisted Suicide Beliefs Won't Affect Panel Recommendations," Huff Post, You http://www.huffingtonpost.ca/2015/07/18/doctor-assisted-suicide-catherine-frazee_n_7823976.html.

[119] Government of Canada Department of Justice, "Consultations on Physician-Assisted Dying - Summary of Results and Key Findings" http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/p6.html#grievous.

[120] Tonda Maccharles, "Assisted Dying to Become Law after Senate Backs Liberals' Bill," thestar,com, https://www.thestar.com/news/canada/2016/06/17/senate-votes-not-to-send-assisted-dying-bill-back-to-mps.html.

[121] Dying With Dignity Canada, "Get the Facts: Bill C-14 and Assisted Dying Law in Canada," http://www.dyingwithdignity.ca/get_the_facts_assisted_dying_law_in_canada.

[122] Government of Canada, "Interim Update on Medical Assistance in Dying in Canada June 17 to December 31, 2017," https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html#intro.

[123] Penney Lewis and Isra Black, "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying Is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon, and Switzerland," *Journal of Law, Medicine & Ethics* 41, no. 4 (2013): 895.

[124] N. Steck et al., "Euthanasia and Assisted Suicide in Selected European Countries and U.S. States Systematic Literature Review," *Medical Care* 51, no. 10 (2013): 938.

[125] N. Steck, Junker, C., Maessen, M., Reisch, T., Zwahlen, M., Egger, M, "Suicide Assited by Right-to-Die Associations: A Population Based Cohort Study," *International Journal of Epidemiology* 43, no. 2 (2014): 614.

[126] Ibid., 621.

[127] Steck et al., "Euthanasia and Assisted Suicide in Selected European Countries and U.S. States Systematic Literature Review," 942.

[128] Margaret Pabst Battin, *Ending Life: Ethics and the Way We Die* (New York: Oxford University Press, 2005), 328-29.

[129] Pam Oliver, "Addressing Access Barriers to Legal Assisted Dying" (University of Aukland, 2016).

[130] Fox, Kamakahi, and Čapek, *Come Lovely and Soothing Death: The Right to Die Movement in the United States*, 328-29.

[131] Ibid., 329.

[132] Ibid.

[133] As one example, see Jerome A. Motto, "The Right to Suicide: A Psychiatrists View," in *Suicide: The Philosophical Issues*, ed. M.P. Battin and D. Mayo (New York: St. Martin's Press, 1980).

[134] James L. Werth, Jr., *Rational Suicide? Implications for Mental Health Professionals* (Washington, DC: Taylor and Francis, 1996), 62.

[135] "Using Rational Suicide as an Intervention to Prevent Irrational Suicide," *Crisis* 19, no. 4 (1998): 186.

[136] Ibid.

[137] James L. Werth, Jr. and James R. Rogers, "Assessing for Impaired Judgement as a Means of Meeting the "Duty to Protect" Whe a Client Is a Potential Harm-to-Self: Implications for Clients Making End-of-Life Decisions," *Mortality* 10, no. 1 (2005): 16.

[138] According to Dr. Werth, this perceived requirement probably stems from the duty some mental health professionals have in some states to prevent harm to others, as set forth in the famous *Tarasoff* cases. In *Tarasoff v. Regents of the University of California,* the parents of a murder victim sued the psychologist who had been treating the murderer because he did not warn the potential victim of the threats against her. The California Supreme Court's 1974 decision in *Tarasoff* established a legal "duty to warn" the potential victim. This ruling was vacated by a subsequent California Supreme Court decision in 1976 that did not mention a "duty to warn" and instead simply stated that a mental health professional had a duty to take reasonable care to protect the potential victim. These cases did not address the issue of possible self-harm. In the 1978 case of *Bellah v. Greenson*, however, the court held that the mental health professional had a duty to take steps to protect the patient from self-harm. In *Bellah*, the parents of a woman who committed suicide with an overdose of sleeping pills sued the psychiatrist she had been seeing. Werth points out that organizations such as the APA, the American Counseling Association, and the National Association of Social Workers frequently tie harm to self with harm to others in their organizational codes of ethics.

In *Bellah*, the court did not specify what steps a mental health professional should take to protect a patient. Instead, it stated that whether or not the steps taken by any given mental health professional in any given situation were satisfactory were up to a jury to decide. What preventive measures are necessary are generally determined by the "standard of care." Unfortunately, the

"standard of care" does not consist of a clearly outlined set of rules. Instead, it is generally determined by judges and juries drawing on established case law and listening to expert witnesses presenting sometimes conflicting testimony in contentious lawsuits. It is not difficult to find advertisements that say, for example, "If you lost a loved one due to mental health care malpractice, speak with an experienced attorney."[138] Given this, it is perhaps no wonder that risk management advisors and malpractice insurance companies advise mental health professionals to take aggressive action to prevent suicide on the part of their patients. After all, while a mental health professional is unlikely to be censored for failing to respect a patient's autonomy or civil rights by committing a patient to a psychiatric facility involuntarily, that same professional runs the risk of damaging and potentially even ending his or her own career should the patient commit suicide.

[139] Thomas Szasz, *Fatal Freedom: The Ethics and Politics of Suicide* (Syracuse: Syracuse University Press, 1999), 86.

[140] Thomas Szasz, *Suicide Prohibition: The Shame of Medicine* (Syracuse: Syracuse University Press, 2011), ix.

[141] Szazs, *Fatal Freedom: The Ethics and Politics of Suicide*, 46.

[142] Wolf, "Physician-Assisted Suicide, Abortion, and Treatment Refusal; Using Gender to Analyze the Difference," 174.

[143] Stefan, *Rational Suicide, Irrational Laws: Examining Current Approaches to Suicide in Policy and Law*, 121.

[144] Ibid., 496.

[145] Ibid., 498.

[146] Ibid., 497.

[147] Ibid.

[148] Ibid., 478.

[149] Ibid., 495.

[150] Elena Lindemans' 2014 video documentary *Mothers Don't Jump from Buildings* is available with English subtitles by permission of the filmmaker, who can be contacted at Elena.Lindemans@bnnvara.nl.

[151] Lisa Lieberman, *Leaving You: The Cultural Meaning of Suicide* (Chicago: Ivan R. Dee, 2003), xii.

[152] Ibid.

[153] Ibid., 43.

[154] Georges Minois, *History of Suicide: Voluntary Death in Western Culture* (Baltimore: Johns Hopkins University Press, 1999), 3.

[155] Ibid.

[156] Ibid.

[157] Szasz, *Fatal Freedom: The Ethics and Politics of Suicide*, 6.

[158] Ibid., xvi.

[159] Ibid.

[160] Szasz, *Suicide Prohibition: The Shame of Medicine*, 3.

[161] Ibid.

[162] Ibid.

[163] Oliver, "Addressing Access Barriers to Legal Assisted Dying," 62.

[164] Ibid., 61-62.

[165] Karolynn Siegel, "Psychosocial Aspects of Rational Suicide," *American Journal of Psychotherapy* XL, no. 3 (1986): 413-14.

[166] Ibid., 414.

[167] Ibid.

[168] Ibid., 415-16.

[169] Ibid., 415.

[170] Liz Szabo, "Death with Dignity Laws and the Desire to Control How One's Life Ends," Washington Post, https://www.washingtonpost.com/national/health-science/death-with-dignity-laws-and-the-desire-to-control-how-ones-life-ends/2016/10/24/6882d1e6-9629-11e6-bc79-af1cd3d2984b_story.html?utm_term=.bedd0e1e1c51.

[171] While this or may not be true for all individuals, perhaps it is true for some. The works of Frankl, Hillman, and Heinz Kohut, who wrote about Sophie and Hans Scholl of the anti-Nazi White Rose student resistance group, have guided some of my thinking about the meaning of autonomy, or what Kohut might have called acting in accordance with the nuclear self. Kohut writes at length about the differences between those he regards as “rational resisters”—resisters to Nazis and to other oppressors—who made strategic decisions about how best to advance their anti-fascist cause, as opposed to those he calls “heroic individuals,” who, he says, “. . . identify their nuclear self, resist the tendency to disown it, and ultimately resolve to shape their attitudes and actions in accordance with the basic design of the nuclear self, despite inner doubts and external threats and seductions.” (Kohut. 2011, p. 140.)

I have wondered whether differences in attitudes toward abortion and self-directed dying result in part from possible differences in approaches to valuing decision-making for the sake of outcomes vs. valuing self-determination almost for its own sake. Presumably, most women who have made a decision to have an abortion have done so because the alternative—carrying a pregnancy to term and having a baby—would have resulted in difficulties such as needing to quit school, marry a man they didn’t want to marry, support another child when their family finances were already stretched very thin, put the child up for adoption, etc.. Surely, it can also be said that many people who have hastened their own death have done so because the alternative—staying alive longer—would have resulted in difficulties such as enduring extreme physical or psychological discomfort, or emotionally or financially burdening loved ones. If, as Siegel suggests somewhat derisively, as Oliver notes more matter-of-factly, and as Frankl and Hillman and perhaps Kohut imply, people who advocate for self-determination, including self-directed dying, may value self-determination or autonomy somewhat for its own sake. Being able to feel in control may be more important to some individuals than it is to others.

Whether the issue is abortion or self-directed dying, advocates have attempted to sway public opinion by presenting arguments that the public can see as “rational” and can, therefore, agree with. (When I worked for NARAL in the mid-1980s, I was instructed to focus discussions of why abortion was needed on the ‘hard cases’ of rape, incest, and other situations in which abortion was the “rational’ choice, and not to discuss it more abstractly as a woman’s right to control her own body and her own life experience.) Like abortion rights advocates before them, advocates of legal aid in dying have, not surprisingly, published

promotional literature (especially personal stories to make the issue real and understandable to the reader) explaining why people might want to hasten death. As Katharina Heyer notes, much of this literature presents avoiding agonizing, unnecessary pain as a reason for wanting aid in dying. Oliver and other authors cited in this dissertation, however, point out that, in fact, escaping pain is cited as a reason for hastening death relatively infrequently, while losing autonomy is cited relatively frequently. Because right-to-die organizations seeking legislative changes surely know that they must justify their reasoning to the public, however, it is not surprising that they focus on pain, as members of the wider public might view avoiding unnecessary paid as a “rational” choice and as a reason more compelling than meeting the dying person’s psychological need to feel in control

Messaging aside, the question of whether members of the public should have to regard another person’s choice (about abortion, self-directed dying, or any number of other things) as “rational” in order to allow it or fail to prevent it may be a question of civil, and human, rights.

[172] Viktor Frankl, *The Unheard Cry for Meaning: Psychotherapy and Humanism* (New York: Simon and Shuster, 1978), 87.

[173] Kathryn A. Smith et al., "Quality of Death and Dying in Patients Who Request Physician-Assisted Death," *Journal of Palliative Medicine* 14, no. 4 (2011): 448-49.

[174] Steck et al., "Euthanasia and Assisted Suicide in Selected European Countries and U.S. States Systematic Literature Review."

[175] Patients Rights Council, "Assisted Suicide Laws in the U.S.," http://www.patientsrightscouncil.org/site/assisted-suicide-state-laws/.

[176] Ibid.

[177] Davis, "Why Suicide Is Like Contraception: A Women-Centered View," 119.

CHAPTER THREE

PARALLELS BETWEEN THE ABORTION MOVEMENT OF THE 1960s AND 1970s AND THE RIGHT-TO-DIE MOVEMENT TODAY

> The subject of assisted death involves a potent mix of health matters, medical involvement, individual autonomy, and life and death deliberations. In that respect, it is connected in many people's minds with other issues that affect women's social and political status, namely abortion . . .[178]
>
> Downie and Sherwin

A comparative analysis of the documents, strategies, and conceptual frameworks employed by the two movements shows that there are many parallels between the abortion movement of the 1960s and 1970s and the right-to-die movement of today. This chapter presents interviews I collected in the 1980s with abortion pioneers of the 1960s and 1970s, along with historic reproductive freedom photos, quotes, and excerpts from documents, and compares them with outreach and education materials used more recently in the right-to-die movement. I used the information presented in this chapter (albeit in a much abbreviated form in my pre-interview materials) to illustrate to the ten veteran reproductive freedom activists interviewed for Chapter Four the many similarities between the abortion and right-to- die movements. (Their feedback about the validity and significance of these comparisons is presented in the next chapter.)

The following section uses a "Then and Now" format. For example:

Then: In the U.S. in the 1960s, assisting a woman in aborting an unwanted pregnancy was illegal in almost all circumstances.[179]

Now: In the U.S. today, assisting someone in hastening his or her own death is illegal in almost all circumstances.[180]

Then**:** When most abortions were illegal, some physicians provided them anyway.[181]

Now: Aid in dying is usually illegal, but some physicians provide it anyway.[182]

The following section addresses three broad themes in terms of similarities between the abortion movement and the right-to-die movement. These are: 1) "how to" resources, including referrals, travel, and books: 2) self-help groups, including menstrual extraction, the Jane Abortion Service, and organizations such as the Final Exit Network; and 3) medicalization, including "therapeutic abortion committees" and questions of reform vs. repeal of restrictive medical laws.

Referrals, Travel, and "How To" Handbooks

Referrals

Then**:** In the 1960s, women seeking abortions could turn to organizations such as the Society for Humane Abortion for information about how to obtain foreign, quasi-legal, or illegal abortions, or how to perform do-it-yourself abortions.[183]

***Now*:** People seeking to end their own lives can turn to organizations such as Exit International for information about how to obtain foreign, quasi-legal, or illegal aid, or how to hasten death on their own.[184]

Some say that the radical U.S. grassroots political movement for abortion began in 1959 when a woman in California named Patricia Maginnis got pregnant for the third time. Maginnis was a very fertile woman, but she did not want to have children. The first time her contraception failed, she went to Mexico, where abortions were illegal but relatively available. The second time her contraception failed, she stuck a catheter – a hollow piece of rubber tubing – up her vagina, through the cervical os (the neck of the womb), and into her uterus. She gave herself a terrible infection and nearly died in the process, but in her sixth month of pregnancy she did finally miscarry. The very next year, Maginnis's contraception failed a third time. Not wanting to run the risk of poking a catheter into her uterine walls again, she instead repeatedly put her finger through the cervical os. She did abort, but had to admit herself to the hospital for post-abortion care. By this time, she was outraged about what needing an abortion meant for women.

Maginnis wanted to change abortion laws, but she wrote, "At that time even mentioning the word abortion was taboo and the mass media avoided the word completely."[185] Maginnis's first step was simply to start people talking about abortion. In the early 1960s she began a one-woman campaign. Standing alone on street corners in California, she conducted the first public opinion poll on

abortion in the U.S. By speaking to people individually and later in groups, Maginnis began to lay the foundation for a grassroots movement for abortion.

Figure 7: News Magazine Talks about Do-It-Yourself Abortion with Maginnis[186]

NEWS MAGAZINE TALKS ABOUT DO-IT-YOURSELF ABORTION WITH PATRICIA MAGINNIS

"Are you pregnant? Is yours a wanted pregnancy? If not, why not see an abortion specialist?"

These jolting questions head a mimeographed instruction sheet distributed by Patricia Maginnis

"Abortion Clinic" recently staged in La Jolla by the San Francisco obstetrics technician.

Here Miss Maginnis discusses with NEWS

Initially, Maginnis had no interest in what she considered the "band aid" work of providing abortion referrals. Her goal was to eliminate laws restricting abortion. Most people were not yet prepared to speak out for this cause, however, and the women who came to Maginnis were mainly interested in ending unwanted pregnancies. In 1964, a woman named Rowena Gurner joined Maginnis in her pro-abortion work and immediately saw the value of using underground referrals as an organizing tool. Gurner remembers an early meeting with Maginnis:

> I went to the apartment where Pat lived and, in her spare time, worked on the abortion issue. It was at that meeting with Pat, or possibly the next one, that Pat showed me a letter she had received from someone in New York. The letter was all about abortion. I looked up at Pat when I finished and said, “Fine. Where’s the answer?”
>
> Pat: I haven’t answered it yet.
>
> Me: (Looking at the date on the letter.) But it’s dated…
>
> Pat: Yes
>
> Me: (I am extremely compulsive.) Would you like me to answer it for you?
>
> Pat: That would be nice.
>
> I type out the answer, show it to Pat who reads it and approves.
>
> Pat holds out a second piece of paper, saying, “Here’s another letter…”[187]

Gurner said, “Before I knew it I was at Pat’s place constantly, playing around with the abortion movement. But it wasn’t playing, it was real.”[188] Gurner became “the general” of the abortion movement. Once she took charge, women seeking referrals were required to donate five dollars and two hours of office work to the movement and to write and sign a pro-abortion letter to their legislators.

In 1965, Maginnis spent an afternoon standing in the rain in San Francisco handing out leaflets to men and women who were leaving a conference on world hunger. One woman, Lana Clarke Phelan, grabbed a flier as she ran to her car to drive 450 miles south to her home outside Los Angeles. When she got there, she un-crumpled the wet mimeographed sheet and saw the words REPEAL

ABORTION LAWS in big letters at the top and a little blurb on abortion laws and on pro-abortion articles distributed by Maginnis and Gurner underneath. Phelan had a keen interest in abortion, having had an illegal abortion during the Depression. As soon as she saw Maginnis's flier she sent away for all the pro-abortion literature it advertised and began a regular correspondence with Maginnis and Phelan.[189] Today Maginnis, Gurner, and Phelan are sometimes called the Three Crusaders or the Army of Three.

The Army of Three gave out thousands of referral lists to women seeking abortions. Maginnis and Gurner produced a list of "abortion specialists," most of whom were in Mexico. Gurner explained, "At first the list contained less than a handful of names."[190] "We gathered as much information on the specialist as possible," she continued.[191] "As the weeks went by, people who learned of our list sent in additional names and information. In this way, the specialist list was constantly updated and expanded."[192] Attached to every list was a sheet of questions that every woman obtaining an abortion was urged to answer after the procedure. "In this way we were able to update the list with the very latest information," Gurner said.[193] "Thus the original one-sheet list eventually ran well over 20 single-spaced typed pages. It was designed to answer every possible question a woman might have about her abortion including tests for pregnancy and post-abortion care."[194]

According to Gurner, the first list had the words, "Are You Pregnant?" at the top. Depending on the situation, the heading was sometimes changed

before the updated list was mimeographed. This was changed depending on the situation. For example, many of the lists were headed with a warning that lists were updated on a daily basis, and that before attempting to use an abortion specialist the woman should send in for the latest list. The lists gave information such as whether or not the abortionist spoke English, whether or not he said he was a physician, costs, hotels in the area and their charges, types of anesthesia, and pre- and post-procedure care. Gurner stated, “On two occasions, a patient seeking an abortion was raped by the doctor. This was noted on the list.”[195]

Just as women seeking to end unwanted pregnancies needed referrals to abortion providers in the 1960s and early 1970s, people seeking to hasten their own death need referrals to sources of information and to drug and inert gas providers today. And, just as referrals regarding abortion resources had to be updated as conditions changed and information was acquired, referrals regarding resources for hastening one’s own death must also be updated as conditions change and information is acquired.

In 2004, Exit International, a right-to-die organization, undertook a survey of its members and discovered that the top two things they wanted in a method of hastening death were reliability and peacefulness. Most who want to be able to consider hastening death would prefer to do so by taking “a pill.”[196] Exit International defines a “Peaceful Pill” as a tablet or mixture that can be taken orally to reliably cause death at the time of one’s own choosing.[197] Peaceful Pills

do exist in the form of barbiturates such as pentobarbital and secobarbital.[198] These are the drugs usually prescribed by physicians in the states and countries where aid in dying is legal. They are strictly controlled and unavailable to the general public. People who cannot obtain prescriptions from physicians legally—like women who could not obtain abortions from physicians legally—seek referrals to alternate sources of assistance.

Exit International provides information about how people seeking to obtain the barbiturates needed to hasten death can get them when they are not legally available. The information covers the pros and cons of ordering drugs online and describes possibilities for obtaining drugs from veterinary pharmacies in other countries. The organization also arranges drug-buying trips to countries where the necessary drugs are more available. Like the underground abortion world, the underground Peaceful Pill world changes frequently. For example, a veterinary pharmacy in Mexico where people once met their needs without incident may at some point become a place of interest to police who might pay taxi drivers, store personnel, or others for tip-offs when Americans shop for barbiturates. Or, an on-line pharmacy that previously supplied the requested drugs reliably might start sending alternate drugs, or no drugs at all.

Just as Maginnis, Gurner, and Phelan collected feedback from women who used abortion providers on their referral list, Exit International organizers collect feedback from people who use resources listed on their referral lists. And, like Maginnis, Gurner, and Phelan, Exit International organizers update their

information constantly. For example, many people who have hastened their own death in the U.S. have done so using Helium. Helium has been readily available for purchase at retail outlets and on the internet in canisters designed to fill party balloons. Inhaling Helium instead of the normal mix of air that contains oxygen causes death from a lack of oxygen, and it does so without creating a feeling of suffocation. Recently, however, Helium suppliers have begun diluting their commercially available products with oxygen. The mixture can still make a balloon float on air, but it is not effective in hastening death. Exit International, the Final Exit Network, and similar organizations now suggest that people seeking to hasten death use not Helium but Nitrogen. At this writing, canisters of Nitrogen designed for use in brewing beer but also suitable for hastening death are available online from various sources including, for example, Max Dog Brewing. The Peaceful Pill e-Handbook is updated every two months, and subscribers also receive e-mails alerting them to drug scams and other changing conditions that might have an impact on people seeking to obtain drugs or other materials to hasten death where legal assistance is out of reach.

Hastening one's own death is a relatively taboo subject in the U.S. Just as Maginnis once asked provocative questions to get people talking about abortion, right-to-die advocates now work to encourage people to talk about self-directed dying. In the undated *News Magazine* article pictured above, Maginnis is quoted as asking, "Are you pregnant? Is yours a wanted pregnancy? If not why not see

an abortion specialist?"[199] Below is a more recent billboard sponsored by the Final Exit Network:

Figure 8: Irreversible Illness? Unbearable Suffering? Die with Dignity[200]

In *Addressing Access Barriers to Legal Assisted Dying,* Oliver points out that reluctance to talk about death, along with misinformation and disinformation about aid in dying by those who are uncomfortable with it or who oppose it are major barriers to people even being able to consider assisted dying as an option. She reports that her interviewees were unanimous in calling for ". . . a louder, broader discussion of (assisted dying) and end-of-life care generally, so that people have more information about the pros and cons of the various options, the stigma associated with ending one's suffering is reduced or neutralized, and people are encouraged to have early considerations and conversations about all end-of-life options."[201] For groups such as the Society for Humane Abortion or

the Final Exit Network, which promote causes considered taboo in the general population, asking provocative questions publicly can serve as a strategy for getting people to think and talk about a subject about which the dominant society discourages discourse.

Travel

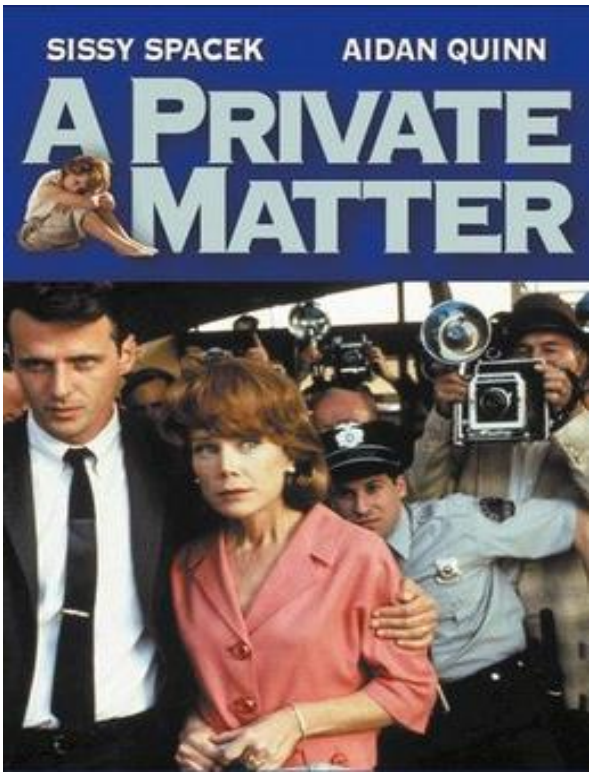
***Then*:** In the 1960s, women who did not qualify for legal abortions in the continental U.S. could, if they had the means, travel to other places where legal abortions, while not guaranteed, were more available.[202 9]

Now: People in the U.S. wishing to receive aid in dying can, if they have the means, travel to other countries where legal aid in dying, while not guaranteed, is more available.[203]

U.S. women's need to seek abortion care outside the country first became a matter of public concern in 1962. Sherri Finkbine, a married, middle-class, white mother of four who was the teacher on a local version of the syndicated *Romper Room* children's TV show discovered that the drug thalidomide, which she had been taking to prevent morning sickness, caused fetal deformity. Unable to obtain an abortion in the U.S., Finkbine flew to Sweden to end her pregnancy legally. Publicity surrounding Finkbine's story was intense. Many historians now credit this publicity with causing Americans to think about the conditions under which women should be able to obtain legal abortions, with most people eventually favoring abortion law reform that went beyond providing legal

abortions only to save the life of the pregnant woman. Finkbine's story was eventually turned into a movie with the tag line, "In 1962, her decision divided a nation. The nation is still divided."

Figure 9: A Private Matter[204]



As this movie poster suggests, Finkbine's story played a major role in making abortion an issue covered by the media and talked about by the public.

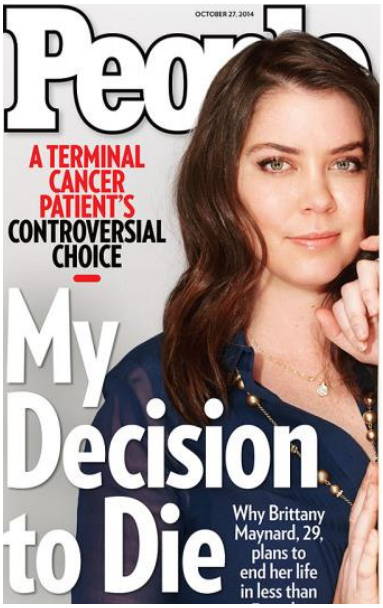
Just as Sherri Finkbine's story drew media attention to the need to travel for abortion care, Brittany Maynard's story drew media attention to the need to travel to receive aid in dying. Maynard, a 29-year-old California woman with terminal brain cancer, moved to Oregon to obtain legal aid in dying. Major

popular media outlets such as *People* magazine and CNN covered her story.

Maynard explained:

> I met the criteria for death with dignity in Oregon, but establishing residency in the state to make use of the law required a monumental number of changes. I had to find new physicians, establish residency in Portland, search for a new home, obtain a new driver's license, change my voter registration and enlist people to take care of our animals, and my husband, Dan, had to take a leave of absence from his job. The vast majority of families do not have the flexibility, resources and time to make all these changes.[205]

Figure 10: A Terminal Cancer Patient's Controversial Choice[206]



Media coverage of Maynard's story brought discussion of assisted dying into mainstream culture in supermarket check-out aisles and newsstands nationwide.

U.S. media outlets such as CNN, Fox, and PBS have also covered the stories of Americans traveling to Switzerland, where legal aid in dying does not require residency and does not require that the person seeking aid be terminally

ill. The press has dubbed this phenomenon “suicide tourism.” For people who have the financial means, traveling to obtain assistance in dying may be an option, just as traveling to obtain assistance in ending pregnancy was an option for Sherri Finkbine. For those without means, it was not and is not. And even for the affluent, having to travel to receive assistance—especially when they are frail or ill—may be less than ideal, given that most people say they want to die at home—and presumably not alone, which may be precluded by expensive travel.

Requiring people to travel large distances to obtain the care they seek, whether an abortion or an assisted death, limits their autonomy, especially if they do not have the physical ability, information, social support, or money to make and carry out the arrangements.

“How To” Handbooks

***Then*:** In 1969, women needing abortions could read *The Abortion Handbook for Responsible Women*, which featured the chapters “Faking the Hemorrhage,” “How to Reach Your Backyard Abortionist,” and “Qualifying for a ‘Legal’ Abortion.”[207]

Now: People seeking to hasten their own death can read books such as *The Peaceful Pill Handbook,* which features the chapters “Carbon Monoxide,” “Hypoxic Death and the Exit Bag,” and “Introduction to Drugs.”[208] [10]They can also

[10] This document contains references to the *Peaceful Pill Handbook,* many editions of which are available in print, and also the *Peaceful Pill E-Handbook,* which is available online by subscription and is updated frequently.

read *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying,* which features the chapters “The Cyanide Enigma,” “Self-Starvation,” “Shopping for the Right Doctor,” “Beware the Law,” “Who Shall Know,” and “After the Self-Deliverance.”[209]

In addition to providing practical information about how to achieve the desired goal (terminating a pregnancy or hastening one’s own death) in the context of a hostile legal system, *The Abortion Handbook, Final Exit, The Peaceful Pill Handbook (*as well as the online *Peaceful Pill E-Handbook)* all emphasize the importance of employing subterfuge. In some cases the subterfuge is designed to trick medical professionals into providing needed care, or at least to provide them with opportunities or excuses to provide care that they are willing to offer but that is against the law. In other cases the subterfuge is needed to protect all concerned against criminal prosecution.

In *The Abortion Handbook,* for example, Maginnis and Phelan wrote:

> FAKING THE HEMORRHAGE
>
> From this moment on, we are pure fraud, and don’t you forget it! We are going to make the best blood-and-guts hemorrhage we know how to put together, and present them with it at the county hospital.… if you appear on the scene with a roaring hemorrhage, you stand a fair chance of getting abortion care without investigations, degradations, and rejections presently meted out by mediocre hospital therapeutic abortion committees and smirking district attorneys.
>
> The first thing you need to know is where and how to borrow blood for your hemorrhage. So, as all women must, we turn to our kitchen for the ingredients.

> “Home-Made Hemorrhage Ingredients”
>
> 2-3 lbs. of raw beef liver, freshly sliced
>
> 1 small syringe (ear or infant)
>
> 3-4 sanitary napkins
>
> Old clothing you can get very bloody
>
> 1 taxicab.
>
> Wash your hands. Scrub your fingernails thoroughly. Don’t wilt or collapse: blood is the stuff of life. Cut the liver into small pieces and squeeze every bit of blood into a clean bowl. Ideally, you need about three cups of blood. If there are clots, so much the better, so do not mash or destroy these. They give an authentic look to your efforts. Tuck a piece of plastic under your bottom so you won’t ruin your rug or bedding. Lie flat on your back with your legs elevated. Prop up pillows if necessary. Tuck the mashed pieces of liver far up your vaginal tract. Take the little rubber syringe, fill it from your interesting bowl of hemorrhage-mix, and squirt your vaginal tract full of as much blood as it will hold…
>
> If you have followed your instructions faithfully to this point, you will not really have to fake weakness and pallor. You already look and feel sick! Acting a “life or death” role is always exciting, so expect an increased pulse rate and do not worry about your pounding heart. Appear worried, confused, and very ignorant of everything. The medical profession loves the image of the dull, cow-like woman, so be what they want you to be.[210]

Like the abortion rights movement, the modern right-to-die movement is often traced to California where, in 1980, Derek Humphry founded the Hemlock Society and ran it out of his garage.[211] Since the founding of the Euthanasia Society of America (ESA) in 1938, the small group of individuals belonging to this organization had called for various forms of assisted dying and euthanasia, but when Nazi atrocities became public knowledge at the end of World War II, the

idea of active euthanasia carried a taint.[212] Consequently, advocates focused on "passive euthanasia," allowing patients to refuse or discontinue unwanted life-prolonging medical treatments.[213] Humphry's Hemlock Society was the first organization in decades to call for "active euthanasia," in which a physician could prescribe and perhaps administer a drug to cause death.[214]

In terms of the need for subterfuge, Humphry's *Final Exit* includes a section headed "Playing Games with the Doctor." As explained above, people wanting the option of hastening their own death generally want drugs, and in the U.S. our legal gateway to those drugs is through doctors. To get the drugs you need from a doctor, Humphry writes:

> You may find that you need to approach your doctor in a round-about way, using the step-by-step approach. Tell your doctor that you cannot sleep, and don't protest when Dalmane or Halcion is prescribed. (They are useful sleep agents but useless in self-deliverance, except in combination with a plastic bag.) Return to the doctor's office a few weeks later and complain that these drugs just do not help you sleep. Could you please have something stronger? The chances are that the doctor will then prescribe something like Restoril, Valium, or Xanax, which are satisfactory for many types of insomnia but completely unsuitable for self-deliverance. Accept this prescription in apparent good faith – you don't have to waste money filling the prescriptions.
>
> Pay a third visit to the doctor and firmly complain that your sleep pattern is not helped by the prescriptions so far. When you see the doctor hesitate, which I'm sure you will, mention that something like Seconal or Nembutal would probably work for you. It is a doctor's task to help you with your medical problems, and there is now no tool left except barbiturates. Have the prescription filled immediately and hoard sixty in a cool, dry place. Be sure it is safe from deliberate or accidental discovery by others.
>
> One doctor told me, "Basically you are duping the doctor. But, let's face it, he may not mind being duped. At least he's not involved

> criminally, because there was no intent on his part to assist a suicide."[215]

In *The Peaceful Pill Handbook,* authors Philip Nitschke and Fiona Stewart point out that, where assisting a suicide is illegal, any person who decides to assist in or be present at the self-directed death of another needs to be very careful.[21611] They recommend that, if possible, the death be made to appear "natural." For example, they write,

> It may . . . be wise to call your doctor for a visit prior to the planned death, complaining of a fever or breathlessness, perhaps some pain on deep inspiration. When the doctor is then called some days later it would be reasonable for them to assume a natural death involving pneumonia.[217]

Other right-to-die advocates suggest that, if the person considering hastening death is indeed terminally ill, he or she enroll in a hospice program. By definition, hospice patients are expected to die, so the death of a hospice patient may be especially likely to be viewed as "natural."

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[11] Which actions constitute "assisting" vary from state to state and are not always clear. For example, a Pennsylvania woman named Barbara Mancini was charged with homicide because when her 93-year-old father, who was on home hospice care, asked her to hand him a bottle of morphine, she did so. Soon after, a hospice nurse arrived and, finding the man unresponsive, had him rushed to a hospital to be revived. He died four days later. Mancini was charged with murder even though it was unclear whether her father intended to hasten his own death, and whether she knew that. The charges were later dropped.

If the death is not likely to appear "natural" to anyone investigating the scene—for example, if the person hastens death by employing a tank of inert gas and an "exit bag" over the head—plans must be made for whether or not to remove the evidence prior to notifying the authorities of the death. In the chapter of *The Peaceful Pill Handbook* entitled "After It's Over," Nitschke and Stewart write:

> If a person ends their life using an Exit Bag, from hypoxia . . . the Exit Bag will need to be removed from the person's head and the Helium canister, along with the tubing and other pieces of equipment will also need to be taken away and concealed. Occasionally Exit members present at Helium deaths remove the gas control fitting from the canister, reattach the black and white nozzle that came with the balloon kit, and re-box the cylinder. This way it appears that the kit had been used to inflate balloons for a party. For a death to appear normal, there must be no evidence of equipment that could have been used in the suicide.[218]

If the person in question was not expected to die, however, they say, "Those left behind by a death are almost always at risk of some form of inquisition. Writing a (suicide) note and storing it in a safe place or with a trusted friend makes a good deal of sense . . . "[219] Alternately, they say that if "the person taking their life does not care that their death be a known suicide, the note can be left alongside their body."[220] A signed, dated suicide note explaining why the person in question wanted to hasten death and stating that the decision to hasten death and the acts involved in hastening death were entirely his or her own might help protect survivors from criminal prosecution.

Self-Help Groups

***Then*:** When most abortions were illegal, lay women organized underground groups to provide safe, affordable, affirming abortion experiences.[221]

Now: Lay people organize in ways some say are outside the law to provide reliable, respectful, peaceful death experiences.[222]

Self-Examination and Menstrual Extraction

In 1969, Carol Downer, a Los Angeles mother of six, heard on the radio that a group of women had chained themselves to the White House to dramatize their demand for equal rights. Downer was not entirely certain what specific rights the women were demanding, but she was excited about the idea that it was possible for women to speak up for themselves, and she decided to attend the next meeting of the National Organization for Women (NOW). ”There were quite a number of women there and they had an abortion task force,” she said.[223] “They had a little form and you indicated what your area of interest was. And since I had had an abortion and really knew how hard it was to locate someone and the whole ordeal, that’s what I was most interested in.”[224] Downer went on to say, “Lana Clarke Phelan was the chair of that task force, and I understudied her. I basically just trotted around after her and listened to her speak, and that was my training to learn about the history of abortion and to think about it.”[225]

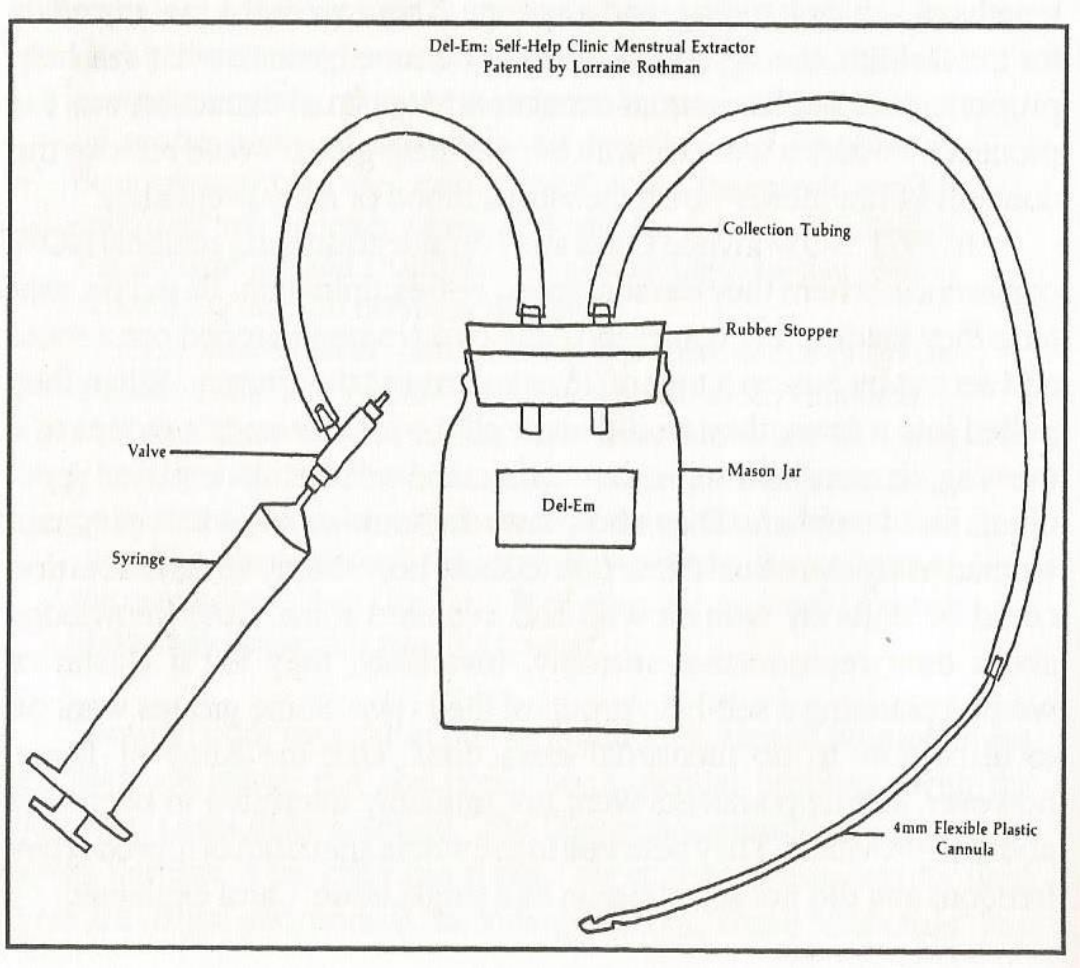
Downer became very active in the Los Angeles chapter of NOW, which regularly provided abortion referrals. Lorraine Rothman, a woman who attended NOW meetings, remembered a meeting at Everywoman's Bookstore at which Downer showed attendees how to use a flashlight, a mirror, and a plastic speculum to see their own cervix, a process that became known as "self-examination." Rothman recalled, "Carol said that she had something really exciting to show us and that it had all kinds of ramifications as far as the direction of any work we would want to do."[226] According to Rothman, Downer led the women into an adjoining room, took her pants off, climbed up on a desk and demonstrated "…how she could, herself, insert this plastic vaginal speculum into her own vagina, and with the use of a flashlight, a simple flashlight, and a hand mirror, she was able to see that portion of her body that had been inaccessible…"

Rothman described how Downer showed the group a plastic flexible straw-like device called the cannula and said that she had seen this used to do suction abortions in an illegal clinic in Los Angeles. Downer explained how the plastic straw-like device was attached to the end of a syringe. Pulling back on the syringe produced suction, and with this straw-like device through the cervix on the uterus, the contents of the uterus could be suctioned out. Rothman concluded, "Well everyone was really excited about how simple this was. 'Of course!'"[227]

Harvey Karman, a psychologist turned abortionist, developed the so-called "Karman Cannula" Rothman described.[228] It was primarily used by skilled illegal abortionists, including doctors. These "criminals" had frequent opportunity to operate the device. In the hands of unpracticed laywomen, it had several drawbacks. For one thing, it had to be held very firmly or it would jiggle and cause unnecessary cramping as suction was applied. For another, the syringe had to be detached from the tubing, emptied, and reattached to the tubing every time it got full. Rothman was concerned that a woman might forget to return the syringe plunger to the correct position before reconnecting it to the tubing and accidentally force air into the pregnant woman's uterus. She said, "I went home and for the next week I started thinking about how to make it a little safer and getting rid of some of these problems. And I started looking in the grocery store and the hardware store and the tropical fish store."[229]

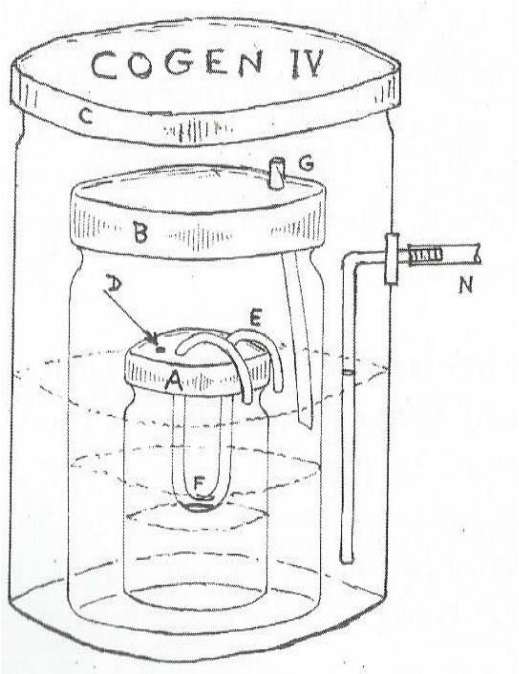
A week later she came back with a mason jar, a cork with two holes in it, two lengths of fish tank tubing, and a syringe. These were the raw materials for the Del-Em, the suction device that became basic to what self-help proponents called "menstrual extraction." Menstrual extraction was the process by which a woman, with her self-help group, could remove the contents of the uterus—be it menstrual blood or early pregnancy tissue.

Figure 11: Del-Em[230]



Today, right-to-die advocates are also in the position of having to create home-made devices to accomplish their goals. For example, the *Peaceful Pill Handbook* includes this drawing of the Co Gen, a carbon monoxide generator that Exit International is developing for use by people seeking to hasten death.

Figure 12: Co Gen[231]



In their description of how to fake a hemorrhage, Maginnis and Phelan were quoted as writing, “So, as all women must, we turn to our kitchen…” Today, the *Peaceful Pill e-Handbook* features videos entitled “Doing It with Betty,” in which an elderly woman called Betty, sometimes wearing an apron, stands in various settings including what appears to be a kitchen, and demonstrates how to concoct various home-made methods of hastening death. In the video still shown in Figure 13, Betty has taken off her apron and put on a nice blouse as she prepares to demonstrate how people can make another device at home—an Exit Bag—for use in hastening one’s own death with an inert gas such as Helium or Nitrogen.

Figure 13: Do It Yourself with Betty[232]

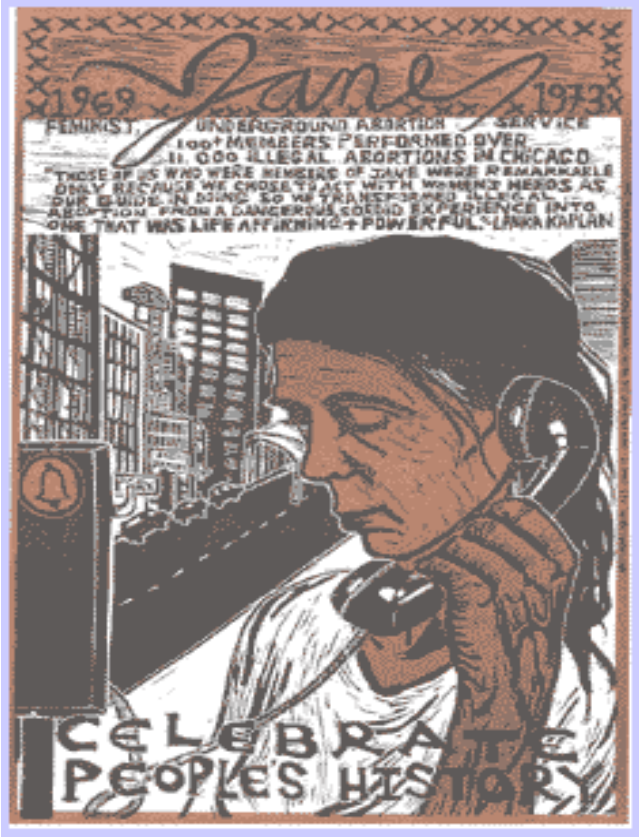
Jane

Self-examination and menstrual extraction groups were one type of self-help organization.

Jane was another.

If you were a poor pregnant woman in Chicago in the early 1970s and you needed an abortion, you might call Jane. Jane was a women's liberation abortion service that performed over 11,000 safe, affordable abortions between 1969 and 1973. Jane would help women when no one else would; at a time when most skilled abortionists charged between $300 and $2,000, this group asked for $100 and received an average of $40. Jane never turned a woman away for lack of funds.[233]

Figure 14: Jane: Celebrate People's History[234]



Jane performed D&C abortions and induced miscarriages. The service started as a referral group by women who were neither doctors nor abortionists. They were mostly middle-class white housewives whose husbands supported them. Sometimes, the women who came to Jane for abortions came back to join the group. In later years, many of the women who joined Jane were young feminists who wanted to work in the women's liberation movement and who could make do with very little income.

Over time, the population Jane served changed. Women with money began leaving Illinois for their abortions once legal abortions without residency

restrictions became available in New York. Women without money stayed in Chicago. Most of the women who came through Jane were poor and Black. In an interview for *Abortion without Apology,* I had the opportunity to speak with a former Jane member who, at that time in the late 1980s, asked to be referred to only as "Jane." Since then, this "Jane," Laura Kaplan, has published *The Story of Jane: The Legendary Underground Abortion Service,* under her own name. In Kaplan's interview she said that the group researched abortionists. One, who claimed to be a doctor, was particularly willing to work with the group. Jane members negotiated with him to lower his price and to allow group members to have more information about and control over women's abortion experience. Kaplan described how Jane members began attending the abortions, sitting with women, and doing "…what you might call 'medical,' we called 'technical' pieces, giving shots, inserting speculums, etc."[235] Kaplan went on to outline an evolution in which women learned abortion techniques and, eventually, discovered that the "doctor" was in fact not a physician. She recalled that members said, "Well, if he can do it, and he's not a doctor, then we can do it," and that they realized that if they could do the abortions themselves, they could charge "a hell of a lot less."[236]

Kaplan said, "Our aim was always to create a very loving, comforting, supportive atmosphere, a reassuring atmosphere, to let this person know that they were going to be alright. . . "[237] At a time when many women obtaining abortions were still forced to wait on street corners, alone, to be picked up by strangers, blindfolded, and undergo procedures in frightening and often unsafe

circumstances, Jane developed a different system. A woman who called Jane for an abortion would meet with a group member to discuss her decision and get the address of a place to go on a particular day. “And this place we called ‘the front’,” Kaplan said. “Because it was a front, and not the place where we actually performed the abortions. It was always an apartment or house that belonged to one of us, or one of our friends, or somebody we knew who’d let us use their house for a day.”[238] Women were encouraged to bring husbands, mothers, friends, children, or anyone else they wanted to provide support. Jane provided services about three days a week, and on any given work day between 20 and 30 women needing abortions were typically scheduled to come to the front. Kaplan said, “So there would be all the women, plus their ‘others,’ at this apartment or house. And there would be a lot of food. There would be, you know, tea and juice and cheese and crackers and cookies, and whatever.”[239] In addition to food, Jane provided information in the form of early newsprint editions of *Our Bodies, Ourselves,* as well as copies of *The Birth Control Handbook* and *The VD Handbook.* Kaplan remembered, “We would load her up with stuff, and if she wanted extras for her friends, you know, our aim was really to get the information out.”[240] “For many of us,” she explained, “it was new information and had really opened our minds. And we wanted to get that information out and share it with as many women as possible.”[241]

At some point during the day, smaller groups of women needing abortions would get into a Jane member’s car and be driven to what Jane called “the

place." "The place" was usually an apartment or house that belonged to a Jane member or a friend who was willing to accommodate visitors for the day. It was the place where abortions were performed.(172)

To Kaplan, what is important about this story is not only that a group of women got together and did something, or even that what they did solved an immediate problem for over 11,000 women. What is most significant to her is *the way* Jane did what it did. She said:

> We wanted to create an atmosphere that was empowering in a situation that was normally very disempowering… We wanted to give women some ammunition in their lives, and, by acting directly, show them that it was possible to take action in their own behalf and in behalf of other women. And do it successfully. And, I might add, at great cost emotionally to everyone who was involved. It's very difficult working in a situation where you have no institutional sanction for what you are doing. And what you are doing is potentially life-threatening. So that you are always on that edge of whether you have the right to be doing what you are doing, but the need is just so great…"[242]

Kaplan stated: "There is always a place for people making decisions and acting on their own behalf and not turning over their own power to other people, whether they have degrees or they have institutions or they have 'the right.' I think we feel too often in this world that we don't have the right to act in our own behalf." She said that one of the most exciting things to her, always, is to get together with a group of people to address a need. She concluded:

> I think that's one of the greatest lessons of Jane. If there's something out there that needs to be done, we don't have to wait until x, y, and z happen. We don't have to beg anybody else to

> please do this for us. We can go ahead and we can do it ourselves.[243]

At this point it may be helpful to understand some background about how both the mainstream political abortion rights movement and the mainstream political right-to-die movements developed in the U.S.

As described previously, after she recovered from her third abortion, Maginnis founded the Citizens Committee for Humane Abortion Laws, later known as the Society for Humane Abortion (SHA). Soon after, she joined forces with Gurner and Phelan and eventually founded the Association for the Repeal of Abortion Laws (ARAL). ARAL grew into NARAL. NARAL was initially an acronym for the National Association to Repeal Abortion Laws and, when repeal was lost (as described later), for the National Abortion Rights Action League. In 1994 the organization again changed the meaning of the acronym to National Abortion and Reproductive Rights Action League, signaling its move away from single-issue abortion rights organizing and toward a broader reproductive rights agenda. In 2003 NARAL dropped the longer name and rebranded itself NARAL Pro-Choice America.

As was the case with ARAL and subsequent abortion rights and women's liberation groups during the second wave of feminism, the Hemlock Society and other right-to-die organizations have undergone a series of mergers, name changes, and splits. For example, in 2003 the Hemlock Society evolved to become End-of-Life Choices, and in 2005 End-of-Life Choices merged with

Compassion and Dying to become Compassion and Choices, the largest right-to-die organization in the U.S. today.

Like activists in the abortion rights movement, activists in the right-to-die movement have faced philosophical and strategic questions and have made different (although not always incompatible) choices. In the abortion rights movement, for example, women such as Maginnis focused primarily (although not exclusively) on increasing public attention on the problem of illegal abortion in an effort to change laws, sometimes by deliberately provoking arrest. Other women, such as those in Jane, tried to avoid mainstream publicity and arrest so that they could continue providing direct assistance to women seeking to end their pregnancies. Similarly, right-to-die activists have taken different positions by focusing primarily on public efforts to change restrictive laws or, alternately, by focusing on more private efforts to provide direct aid.

The first major legal breakthrough for the right-to-die movement came in 1994 when Oregon voters passed a ballot measure approving the Oregon Death with Dignity Act. The measure was returned to the ballot by the legislature where it passed again in 1997 and became law. Important as it was, however, the Act did not declare that individuals had a right to control when and how they died. Instead, it set out the conditions under which a subset of people could legally receive aid in dying from physicians.

Over time, right-to-die groups have split again, perhaps most importantly when Compassion and Choices elected to jettison active “do-it-yourself” methods

of ending life. Compassion and Choices has become a leader in legalizing what it terms “physician aid in dying.” (In a move reminiscent of the adoption of the term “pro-choice” instead of “pro-abortion,” this public relations maneuver drew on message testing showing that the public had a negative association with the word “suicide” and that the phrase “physician aid in dying” would be more palatable to the public than the phrase “physician-assisted suicide.”)

Those who stayed with Compassion & Choices agreed with a strategy of focusing primarily on legalizing physician aid in dying for the subset of people who met the Oregon criteria, and on a less well-publicized strategy of providing information about other constitutionally-protected means of hastening death (such as voluntarily stopping eating and drinking), again to people who met the Oregon criteria. In recent years Compassion and Choices has also promoted the use of advance medical directives and has pushed to encourage doctors to have more frank and open conversations with patients that might help them avoid unwanted treatment. Those who left to form the Final Exit Network, on the other hand, established the only organization in the U.S. willing to provide assistance to people who were not terminally ill. Because no state in the nation allows physicians to prescribe medication to these individuals, the Final Exit Network provides information about non-medical means of hastening death, such as inhaling Nitrogen in place of oxygen, and members have sometimes been charged with the crime of assisting suicide or even of committing murder.

To the extent that comparisons are possible, one might think of Compassion and Choices as the NARAL-like arm of the right-to-die movement and of the Final Exit Network as the Jane/women's-self-help-movement-like arm of the right-to-die movement.

Medicalization, Therapeutic Committees, and Reform v. Repeal

Medicalization

Abortion was not illegal in the U.S. before the nineteenth century.[244] The practice of abortion before "quickening" (the point at which the pregnant woman could feel fetal movement, usually around the fourth month of pregnancy) was widely condoned. The developing medical profession shaped the evolution of anti-abortion policy.[245] In the early decades of the nineteenth century men who had perhaps been to only a few months of medical school wanted to establish themselves as "regular" physicians. They perceived female patients as the gateway to family practice. "Regular" physicians saw "irregular" physicians (homeopaths and others critical of the European-trained "regulars") and midwives as obstacles in their path. "Irregular" physicians and midwives had traditionally provided obstetrical and gynecological care, including abortion. With the establishment in 1847 of the American Medical Association (AMA), doctors gained an organizational and lobbying vehicle through which to mount effective legislative pressure to discredit "irregular" physicians and midwives and place gynecological care, including abortion, under the control of "regular" physicians.

The AMA helped “regular” physicians gain access to the higher status and income granted by professionalization.

Medical professionalization alone does not explain why, by the 1880s, many states had passed severe anti-abortion laws, generally making the procedure illegal unless it was necessary to save the life of the mother. Theoretically, “regular” physicians could have discredited midwives and others who had traditionally provided abortions but continued to perform abortions themselves. Throughout the time middle- and upper-class white male physicians were professionalizing, however, eugenicists were spreading alarm about the fact that middle-class white Protestant women had been seeking abortions in increasing numbers. During the Progressive Era eugenicists feared “race suicide,” specifically the decline of the native-born white middle-class population during a period of high immigration. In their book *Reproductive Justice: An Introduction,* Loretta Ross and Rickie Solinger argue that a key reason for outlawing abortion was to “. . . make sure that white women brought their pregnancies to term and so gave birth to all the white children necessary for populating the white nation.” [246] Laws criminalizing abortion were passed and remained unchanged and virtually unchallenged for nearly a century.

Like abortion (not to mention childbirth), suicide – both assisted suicide and suicide prevention - has become increasingly medicalized. Although deliberately hastening one’s own death has not always been viewed negatively in all times by all cultures, in European and American culture suicide has historically

been viewed as a crime or a sin. In each case, life has not been seen as belonging to the individual experiencing it. During the Middle Ages under the system of manorialism, for example, serfs and their labor were viewed as belonging to the lords of the manor. The suicide of a serf robbed the lord of what was rightfully his. Suicide was criminalized. As punishment, the body of the person who had committed suicide was dragged through the streets. Perhaps more importantly, any property left behind by the person who committed suicide was confiscated and given to a lord or other magistrate as compensation for his loss.[247]

The view that manors or fiefdoms own the people who work within them is no longer widely articulated today, and now suicide is not a crime in any state. It is still, however, often considered to be a sin. Those who believe that God creates and owns human life and that He alone has the right to take it away may view suicide as stealing from God.[248]

Many professionals, however, now regard suicide as a medical, mental health, and/or public health problem. Suicide is widely considered to be a negative outcome to be prevented in virtually all circumstances, and people who contemplate hastening their own death are assumed to be incompetent. For many, the idea that an individual might hasten his or her own death is, *ipso facto,* proof of mental illness. Dr. Szasz writes, “Rejecting life and wanting to kill oneself is defined as a severe mental illness characterized by ‘dangerousness to self,’ and is treated as a quasi-crime with coercions called “treatments” (especially

involuntary “hospitalization” and forced drugging).[249] “For our society,” he continues,” suicide is, first and foremost, an act of *lèse majesté* (literally, ‘injured majesty’).”[250] He continues, “Webster defines the term ‘*lèse majesté’* as ‘an offense violating the dignity of a ruler as the representative of a sovereign power; detracting from dignity or importance as a constituted authority.’”[251] For millennia,” Szasz explains, “suicide was *lèse majesté* against the Church-State, the supreme representation of a legitimate authority for people who worship a god and who want a good life in the hereafter.”[252] “Today,” he concludes, “suicide is *lèse majesté* against the Therapeutic State, the supreme representation of legitimate authority for people who worship health and want to stay alive as long as possible.”[253]

Therapeutic Committees

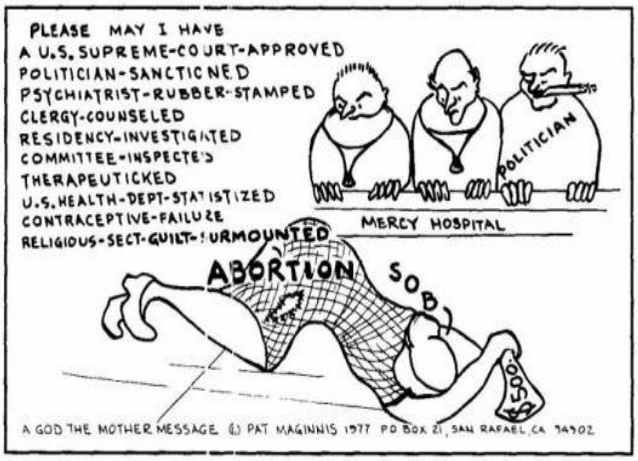
***Then*:** In the late 1960s, legal abortions were available in a small number of states to women who could receive aid from physicians, usually after convincing a “therapeutic abortion committee” that they met its criteria.[254]

Now: Legal aid in dying is available in a small number of states to people who can receive aid from a physician, usually after convincing two or more doctors that they meet that state’s criteria.[255]

After anti-abortion laws took hold in the U.S. women continued to terminate unwanted pregnancies, albeit at great social, economic, and physical costs, including death. In 1959, the American Law Institute (ALI), a national nonprofit whose goal it was to “rationalize” legal processes, drafted a model

statute that expanded the conditions under which a woman might be granted a legal abortion. The ALI bill would permit physicians to perform abortions in cases where a woman could convince a hospital “therapeutic abortion committee” that her pregnancy resulted from rape or incest, that it endangered her life or her physical or mental health, or that the fetus was deformed.[256] The ALI bill was first introduced into a state legislature in California in 1961. Although the bill did not pass until the mid-1960s, it enjoyed increasing support among professionals in the early 1960s. During those years a thalidomide scare and a rubella epidemic drew public attention to the demand for abortion on grounds other than preserving the life of the mother. This bill did not speak to the needs of the majority of women seeking abortions, but it did expand acceptance among professionals of the concept of “therapeutic abortion committees” as medical and administrative bodies able to make decisions about whether a given woman should be able to receive legal aid in terminating a pregnancy.

Figure 15: God the Mother Message – Therapeutic Abortion[257]

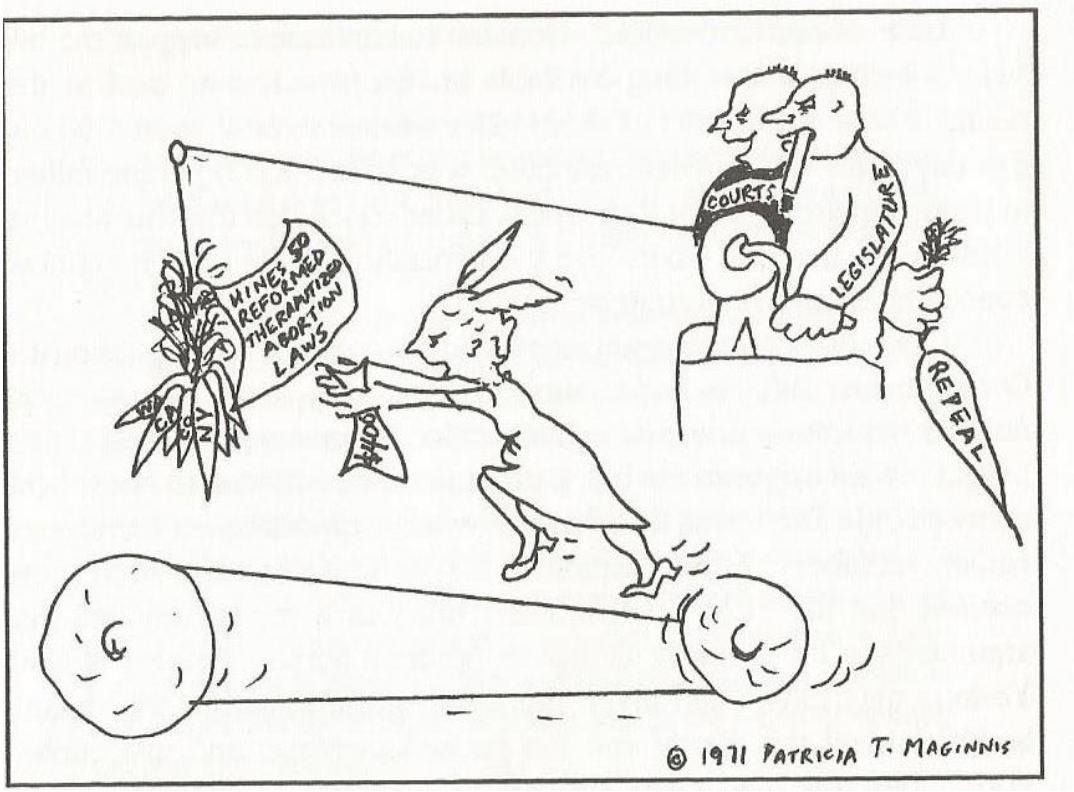


Today, while the American states that have legalized receiving aid in dying have not established aid-in-dying committees *per se,* they do typically require that at least two and sometimes three or more health care professionals grant approval. The Oregon Death with Dignity Act, which has become a model for the other states that have liberalized aid in dying laws, did not declare that individuals had a right to control when and how they died. Instead, like the 1959 model ALI abortion law reform bill, it set out the conditions under which a subset of people could receive aid if they convinced physicians that they fulfilled restrictive legal requirements.

Reform v. Repeal

Patricia Maginnis may have been the first activist to articulate a goal of repealing abortion laws. In 1961, she reluctantly supported the ALI model abortion reform bill introduced by California State Senator John Knox. Maginnis remembers, “I got sick inside every time I had to look at it. But I had to look at it, because what else was there?”[258] By 1963, however, Maginnis opposed the ALI reform, stating, “I am not out to legalize abortion! I am out to repeal abortion laws!”[259]

Figure 16: God the Mother Message – Reform/Repeal[260]



The work for abortion law repeal begun by Maginnis, Gurner, and Phelan in California was carried on most successfully in New York in 1970, by which time the women's liberation movement had mushroomed across the country. New York abortion law repeal activist Ellen Willis is quoted as saying, "When the radical feminist campaign for repeal of the abortion laws began in 1969, our first target was the 'reformers' who sat around splitting hairs over how sick or poor or multiparous a pregnant woman had to be to deserve exemption from reproductive duty."[261] "It was the feminist demand for the unconditional right to abortion that galvanized women and created effective pressure for legislation."[262] Author Brett Harvey states, "In 1970 a group of New York area feminists

distributed a copy of a 'model abortion law': a blank piece of paper." "Their position was unequivocal: a woman's right to abortion must be absolute," she said," because her very personhood depends on her ability to control her own reproductive system." [263]

In her article about the abortion law repeal campaign in New York, "The Power of History," Kathie Sarachild writes, "It was the radical strategies of 1) opposition to reform and demand for repeal, led by Lucinda Cisler, 2) mass consciousness-raising on abortion with women testifying to their "criminal" acts in public and in court, and 3) the development of the feminist self-help clinic ideas and their promotion of simpler new abortion techniques that led to the national reform in five years time . . . "[264] Cisler said, "There had been abortion groups in many different states, mostly reform. Some were repeal groups like Pat Maginnis and Lana Phelan's group out in California"[265] "We—New Yorkers for Abortion Law Repeal—were started by New York-NOW…," she continued.[266] "So New Yorkers got started and people from Ethical Culture and the Civil Liberties Union and the Humanists and the Unitarians and all kinds of people and people from all around the state joined…"[267]

Cisler remembered, "At first people who were already in the abortion movement who'd worked on reform were somewhat leery to bring it up—believe it or not—as a woman's issue… They'd say, 'That will scare the legislators…'"[268] "But what is it, you know?" she continued.[269] "It is a public health issue, it is a doctors' rights issue, it is a population control issue, it is all those other things,

but finally it's this damn woman who is pregnant and who doesn't want to be pregnant and she's going to do something about it…"[270] She said that "the boldness" of saying, "It's my right!" was "the spark that made the already existing current of older abortion reformers take light and see that there was a possibility of something they had never even dared dream about—or if they did they'd quickly draw in their horns and say, "Oh, we'll never get that far."[271]

Some segments of the right-to-die movement, too, speak with such boldness. For example, in his article, "Suicide: A Civil Right," Lawrence Stevens says, "Whether or not a person supports the right to commit suicide is a litmus test of whether or not that person truly believes in self-ownership and the individual freedom that comes with it, the individual freedom that many of us have been taught is the reason-for-being of American democracy."[272]

In 1969, when a bill was introduced into the New York State legislature containing a series of deletions repealing abortion laws from the criminal code, the different wings of the abortion movement were one big happy family. In 1970, when the bill's sponsor changed the bill from repeal to broad reform, activists faced a difficult choice and made different decisions. The revised bill stipulated that abortions had to be performed by physicians and that abortions could not be performed after the 24th week of pregnancy unless the woman's life was in danger. NOW leaders at the national level urged continued support of the bill. The newly formed National Association for the Repeal of Abortion Laws disapproved of the changes but elected to back the bill anyway. New Yorkers for

Abortion Law Repeal maintained its support for repeal and opposition to reform. Cisler recalled, “We were considered just horrible people who wanted women to die. We wanted women to be left bloody and mangled on the street…”[273] “We were portrayed as people who wanted everybody with a coat hanger to do an abortion, which was nuts, because that wasn’t our viewpoint. [Our view] was, ‘Leave the door open for the world to develop as it is about to do.’”[274]

Proponents of the abortion reform bill asserted that the limitations that abortion be performed by a physician before 24 weeks of pregnancy “would only affect a handful of women.” About this “handful,” Cisler remembered, “After the law was changed, our group got people calling us looking for late abortions. All the abortion counseling and referrals that I did and that anyone ever did kept us going. Because it kept being individual women saying, “Things aren’t working right for me…”[275] She cited people who accepted reform as saying, “’Only two percent of women get late abortions anyway,’ essentially saying, ‘To hell with those women.’ Nobody who was for repeal ever said to hell with anybody. Every woman is a one hundred percent sample of herself.”[276]

Speaking about the period after the abortion law reform bill passed in New York, Cisler recalled, “There was one of the usual, somewhat careless, well-meaning polls which said to a good cross-section of the public, ‘In New York State now any woman who wants an abortion can get one legally. What do you think about that?’ Of course it wasn’t true. That’s what we’d been for!”[277] “Oh,”

she continued, “most people thought that was just fine—as they would have if someone maybe actually had tried to pass that!”[278]

When the campaign for repeal broke into bitterly opposed factions in the 1970s, Cisler wrote an article entitled, “Abortion Law Repeal (sort of): A Warning to Women.” She explained: “The abortion issue is one of the few issues vital to the women’s movement that well-meaning people outside the movement were dealing with on an organized basis even before the new feminism began to explode a couple of years ago. Whatever we may like to think, there *is* quite definitely an abortion movement that is distinct from the feminist movement, and the good intentions of the people in it can turn out to be either a tremendous source of support for our goals or the most tragic barrier to ever achieving them.”[279] Throughout the article, Cisler warned that abortion supporters who did not share the core goal of self-determination for women would be tempted to accept token gains, and argued that as long as the government maintained a voice in the abortion debate it would use its power to chip away at each woman’s right to make her own choice about abortion. Her predictions have come true with a vengeance.

Today in the right-to-die movement, the mainstream political strategy is reform rather than repeal of assisted dying laws. By contrast, in the abortion movement, the fight for repeal instead of reform had an impact on the abortion debate nationwide until the conclusion in 1973 of the *Roe v. Wade* lawsuit. In *Roe,* the U.S. Supreme Court vastly expanded the conditions under which a

woman might be allowed an abortion, but it stopped short of endorsing the idea that each woman had the absolute right to control her own body. Rather than leaving the abortion decision up to each woman, the Court stated that the decision was protected by the right to privacy between a woman *and her doctor* and it stated that the government could restrict or even prohibit abortion under certain circumstances.

After New York State adopted abortion law reform rather than repeal in 1970 and Cisler published "Abortion Law Repeal (sort of): A Warning to Women,"[280] Harvey notes, "Though radical feminists warned that the limited nature of the victory made it vulnerable to erosion and even reversal, most of us assumed in 1973 that the battle was over—that our right to abortion was secure."[281] She goes on to point out that the Cassandras were right. In the mid-1970s, legal restrictions began to chip away at women's access to abortion. With the women's liberation movement dwindling and the political climate shifting to the right, many abortion rights advocates began focusing not on women's fundamental right to bodily autonomy but instead on the "hard cases" of rape, incest, dire health risks, and fetal deformity. Some groups, such as NARAL, focused on single-issue organizing in an attempt to defend the gains that had already been made. In an effort to soft-sell abortion in changing political times, activists adopted the term "pro-choice," a move some veteran organizers claimed made abortion "the right that dare not speak its name."

Today, women seeking abortions face an increasing number of restrictions such as parental notification and consent laws, waiting periods, strict time limits, and requirements that they view the fetus via ultrasound, and fewer facilities providing abortions as clinics close due to stringent new building regulations.[282] And today, even in states where aid in dying for terminally ill, mentally competent resident adults is legal, eligible patients face mandatory waiting periods and bureaucratic requirements. Patients who do not meet the Oregon requirements are legally left to fend for themselves.

Reproductive Justice

Then*:* In the late 1960s and early 1970s, primarily middle- and upper-class white women led and supported the mainstream abortion rights movement.

Now: Primarily middle- and upper-class white people lead and support the mainstream right-to-die movement.

Women of color were involved in reproductive freedom activities in numerous ways before, during, and after the 1960s and 1970s. Their activism sometimes took place within the context of nationalist movements rather than the predominantly white feminist movement, and their positions were often informed by their race and class struggles. Beginning in the late 1980s, reproductive justice groups organized and led by women of color pushed mainstream predominantly white abortion rights groups to address reproductive freedom issues that were priorities for them.[283] The reproductive justice movement brought attention to the limitations of the right to privacy as a foundational

argument for choice in reproductive decisions, it linked reproductive freedom to social justice, and it introduced a human rights framework into the discussion of abortion and related issues.[284]

The reproductive justice perspective informed the reproductive freedom struggle. The section below focuses on three of the many lessons the movement for self-directed dying might learn from the reproductive justice movement. They are: 1) the rejection of population control; 2) the limitations of single-issue-organizing in the pursuit of meaningful choice; and 3) the importance of including the perspectives of diverse stakeholders earlier rather than later when developing a movement.

Population Control

Organized U.S. movements for birth control and for what was sometimes called “death control” both emerged during the Progressive Era in the 1910s.[285] While the birth control movement garnered support not only from elite Progressives but also from the grass roots, the death control movement continued for decades to be led and supported primarily by a small number of activists, most from the upper classes and many interested in eugenics.[286] Like many others in North America and Europe, these reformers believed that new scientific ways of thinking (as opposed to old religious ways of thinking) could help engineer societies that would bring the most good to the most people.[287] In both the early birth control movement and the early death control movement, some leaders espoused the importance of each individual’s freedom to self-

determine the course of his or her own life. Theologian Joseph Fletcher, who published *Medicine and Morals,* for example, said, “Death control, like birth control, is a matter of human dignity. Without it persons become puppets.”[288] Others used paternalistic arguments to explain why birth control or death control would be a benefit to underprivileged or unfortunate individuals. Dr. Harry J. Haiselden, who had performed sterilizations on several boys and girls at the request of their parents, for example, publicly promoted the practice of mercy killing of deformed infants, arguing that if they were allowed to live their lives would only be filled with suffering.[289] Still others proposed that the need of society to be free from the burden of coping with underprivileged or unfortunate individuals superseded the rights of those individuals to reproduce or even to continue living. William J. Robinson, a physician and birth control advocate who endorsed infanticide, for example, in discussing infants with deformities and people living with hereditary disabilities, stated, “Such individuals have no rights. They have no right in the first instance to be born, but having been born, they have no right to propagate their kind.”[290] Many death control advocates made several or all of these arguments. Charlotte Perkins Gilman, for example, supported the idea of “social surgery” through euthanizing “the grossly unfit,” and also believed that most people should be able to choose the time, place and means of their own death; when she became terminally ill, Gilman killed herself, stating that she “preferred chloroform to cancer.”[291]

One thing common to different reproductive justice groups in the 1980s and beyond was that the women who led them rejected the use of abortion, contraception, and sterilization as tools of population control.[292] While many able-bodied middle- and upper-class white women experienced contraception, sterilization, and abortion as welcome ways of controlling their own bodies and increasing their own autonomy, many poor women, disabled women, and women of color experienced contraception, sterilization, and abortion as tools of those in power to control populations seen as undesirable.

People whose lives are viewed as being somehow not worth living, or who are seen as a burden on society, have not only been subjected to involuntary sterilization in the past but continue to receive different and sub-optimal medical care today. This is true not only for people of color and poor people but, perhaps especially, for disabled people.

People living with disabilities have experienced a long history of forced sterilization. In 1883 Sir Francis Galton coined the term “eugenics” to describe his pseudo-science of “improving the stock” of humanity.[293] The eugenics movement gained traction in the U.S, and in 1907 Indiana passed the first compulsory sterilization law.[294] In 1927, the U.S. Supreme Court *Buck v. Bell* decision upheld a Virginia law allowing for sterilization without consent of people found to be “feebleminded, insane, depressed, mentally handicapped, epileptic and other.”[295] The Court found that forced sterilization of people with disabilities

did not violate their constitutional rights.[296]/[12] Nationally, twenty-seven states began wholesale sterilizations of people considered undesirable for a wide range of reasons, and by the 1970s over 60,000 people had been sterilized without their consent.[297]

While forced sterilization of disabled people is no longer as common, today many pregnant women at increased risk of carrying a fetus with abnormalities, such as women 35 and older, are encouraged to undergo an ultrasound and amniocentesis early in the second trimester of pregnancy. Together, these tests can reveal anatomical conditions such as cleft palate and heart defects, and chromosomal abnormalities and neural tube problems such as those leading to Down syndrome. Some women who discover that the fetus they are carrying has some degree of abnormality elect not to carry the pregnancy to term. Although feminist disability rights advocates such as Adrienne Asch and Michelle Fine argue that women must be able to access abortion for any reason, including fetal abnormality, they call on mainstream pro-choice activists not to exploit disability as a good or compelling reason to keep abortion safe, legal, and

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[12] In 1933 the German Law for the Prevention of Genetically Diseased Offspring was adopted and the Nazi sterilization program began. Six years later, Nazis replaced it with a euthanasia program under which tens or perhaps hundreds of thousands of people, including roughly 5,000 children, were put to death (Adams, 2007). Technology developed through the euthanasia program was eventually used for mass killings of Jews and others during the Holocaust.

funded, insisting, “Abortion must be safe, legal, and funded on the basis of women’s rights alone—not to rid our society of some of its “defective” members.”[298] They also point out that many people with biological limitations assert that “their main obstacles to fulfilling lives stem not from these limitations but from a society that stresses mental and physical perfection and rugged individualism, that often rejects, isolates, and segregates them, assuming that disabled people are unpleasant, unhappy, hopeless, and burdensome.”[299]

A large body of literature documents the many ways that people living with disabilities continue to face prejudice and discrimination. Medical professionals, for example, tend to assess the quality of life of disabled individuals as being far lower than people living with disabilities do themselves.[300] It would not be surprising, therefore, if these medical professionals unconsciously or consciously considered withdrawal of treatment or even physician-assisted dying for disabled patients sooner than they would consider these options for non-disabled patients. While withholding or withdrawing life-sustaining treatment due to medical futility may not always require the informed consent of the patient, physician-assisted dying as it exists in the U.S. today does require that the patient request this option voluntarily. Some disability rights advocates suggest, however, that as a result of societal prejudice and discrimination against them, disabled people might be more likely to request, and physicians might be more likely to grant, a prescription for a lethal dose of medication. Disability rights advocate Nancy Mairs, for example, asks, “If, ideally, I ought never to have been

born, and if my dependent existence creates a burden on those who must care for me, then don't I have not merely the right but the obligation to die?"[301]

Prejudice against people living with disabilities is not limited to medical professionals. Disabilities that require individuals to depend on others for assistance, including financial assistance but perhaps especially assistance in the activities of daily living, such as toileting, may be viewed both as placing a burden on others and as creating a situation of indignity for the disabled person. Under the heading "Better Dead than Disabled?" Katharina Heyer writes,

> I began to notice that when assisted suicide advocates really wanted to scare their audience, they did not use unremitting pain to do it. They use disability. The need for help to go to the toilet was the big stick. Wouldn't you rather die than have someone else wipe your butt? It never seemed to cross those advocates' mind that thousands of people in the United States get help to wipe their butts every day.[302]

In fact, some people who hope for the option of assisted dying (sometimes called "Death with Dignity") for themselves desire aid in dying not because of fear of pain but for many other reasons such as fear of loss of independence and dignity, including loss of the ability to manage urination and defecation on their own. Some disability rights activists believe that the right-to-die movement's tag line, "Death with Dignity," exploits widespread societal stigmatization of disability, reinforces prejudicial attitudes that disability is synonymous with indignity, and implies that disability is a fate worse than death.[303]

Another disability rights critique of physician-assisted dying focuses on the idea that the liberal concepts of autonomy, privacy, and choice that form the

foundation of many arguments for legal aid in dying cannot be accepted uncritically in economic, social, and medical conditions of inequality that disadvantage people living with disabilities.

In her article, “The Cultural Logic of Euthanasia: ‘Sad Fancyings’ in Herman Melville’s ‘Bartleby,’” Rosemarie Garland-Thomson describes the different situations, decisions, and meanings to the American public of two people confronted with disabilities. One, Roosevelt Dawson, a 21-year-old African American man from a financially-stressed family who had become quadriplegic 13 months earlier as a result of a viral infection, chose to end his life with the assistance of Jack Kevorkian. The other, former *Superman* star Christopher Reeve, chose to live and dedicate much of his life to trying to find a cure for disability caused by spinal cord injury. Garland-Thomson, citing the “American imperative for self-determination,” notes that the public seemed to agree both with one disabled person’s (Dawson’s) decision to die, and also with the other disabled person’s (Reeve’s) decision to live.[304] Pointing out the differing economic, racial, and cultural capital available to the two men, she describes how Reeve was able to parlay such capital not only into expanded personal options but also into a search for a cure. This purpose, she argues, resonated with Americans because it represented the “sacred cultural ideologies of progress, self-determination, improvement, reform, and perfectibility—in other words, the very essence of what we take to be American.”[305] With his relatively scant resources, one the other hand, Dawson was viewed as unfixable.

This American emphasis on “progress” and “improvement” surely played an important role in the uptake of eugenics during the Progressive Era. In his book, *A Merciful End: The Euthanasia Movement in Modern America,* Ian Dowbiggin notes, “By the 1920s, the United States had become perhaps the world’s most eugenic nation.”[306] The American belief in “progress” and “improvement” may now serve as a double-edged sword in American attitudes toward self-directed dying.

On one hand, the belief that (whether through science, medicine, or social engineering) we can always make reforms and improvements or find a cure may encourage some physicians to offer continuing but likely futile, expensive, and debilitating treatments to dying patients to prolong their lives. It might simultaneously discourage them from accepting and helping ease an impending death; if doctors perceive death as an enemy to be held at bay, death’s victory may equate to the physician’s failure. Dr. Nuland, cited above, writes that “. . . the fantasy of controlling nature lies at the very basis of modern science. . . . None of the acts of nature (or Nature) is more hostile than death. Every time a patient dies, his doctor is reminded that his own and mankind’s control over natural forces is limited. . .” [307] In *Death, American Style: A Cultural History of Dying in America,* Lawrence Samuel writes, “The notion of one day disappearing is contrary to many of our cultural values, I propose, with death and dying viewed as profoundly ‘un-American’ experiences.”[308] He concludes, “. . . if there is one

single idea that summarizes the literature devoted to death and dying in America over the last half century or so, it is denial."[309]

At the same time, the idea that something that cannot be "improved" or "perfected" but must instead be accepted and accommodated does not fit the liberal, progressive narrative of America. It is not a big jump to conclude that what does not fit the American narrative should be eliminated.

Both people with disabilities and people of color have been targeted for elimination in various ways at various times, and the concerns expressed by disability rights activists are similar to those expressed by women of color in the reproductive justice movement. Both critiques frame health care choices not only or even primarily as issues of legal civil rights but rather as issues of broad human rights.

Like disabled women, women of color have been the targets of population control efforts. These efforts include the manipulation of access to contraception, abortion, and sterilization and are embedded in broader histories of population control efforts experienced in different ways by women of different ethnicities.

For example, African American women, under slavery, could be raped and/or forced to reproduce for the pleasure and profit of their white slave owners.[310] After emancipation, when the birth of Black babies no longer increased slave owners' holdings in human chattel, white southerners expressed fears about possible increases of the Black population.[311] Black women had been viewed as immoral and lascivious, and that myth was systematically perpetuated

after slavery ended.[312] They were often seen by whites not only as procreating with abandon, with no interest in limiting their own fertility, but as being neglectful mothers who tended toward quantity rather than quality when it came to bearing and raising children.[313] According to popular stereotypes in the twentieth century, if Black women attempted to control their own fertility at all, it was to produce more children in order to fatten their welfare checks at taxpayers' expense.[314]

The economic crisis of the Depression and the subsequent New Deal increased whites' interest in limiting the birth of children likely to require welfare, and eugenicists and others began to focus more attention on preventing births to poor Black women.[315] Contraceptive clinics funded by the government and by private foundations were often located in majority Black neighborhoods. These clinics were met with mixed reactions from Black women and men, perhaps especially in the 1960s and early 1970s when the Black Panthers and others interested in Nation Building sometimes viewed contraception, abortion, and sterilization as tools of genocide against Black people.

Although deeply concerned about racism, many Black women leaders disagreed with the idea that all Black women should reject contraception and sterilization. In 1969, Frances Beal, an organizer for the Student Nonviolent Coordinating Committee, published a pamphlet entitled, "Double Jeopardy: To be Black and Female." This pamphlet, which addressed issues of racism and poverty as well as sexism and was republished in multiple anthologies, called for

legal, accessible contraception and abortion and an end to sterilization abuse, and it lay the foundation for a new discourse on reproductive justice.[316]

In 1973, press accounts of reproductive rights abuses targeting African Americans gained the attention of white Americans. The Southern Poverty Law Center sued when fourteen-year-old Minnie Lee Relf and twelve-year-old Mary Alice Relf were sterilized without their or their parents' knowledge or consent. The lawsuit documented and publicized the extent of sterilization abuse by health care providers against Black women, thus confirming what many Black women had long believed. A decade previously, Civil Rights activist Fannie Lou Hammer had popularized the phrase "Mississippi Appendectomy," referring to involuntary sterilization procedures in which African American women seeking treatment for conditions such as appendicitis might be sterilized without their knowledge. Countless anecdotes also existed of women being coerced into receiving tubal ligations or hysterectomies.

Also in the 1970s, *Roe v. Wade,* which vastly expanded access to abortion, was quickly followed by the Hyde Amendment, which prohibited the use of federal Medicaid funds for abortion, thus reducing access to abortions for poor women, who were disproportionately women of color. Sterilizations, however, continued to be covered.

Currently, reproductive justice activists note that long-acting reversible forms of birth control, such as the IUD and Norplant, which must be removed by physicians, may be disproportionately marketed to African American women,

perhaps based on (and perhaps also perpetuating) the view that African American women should, but on their own are not inclined to or able to, limit their fertility. Also currently, many reproductive justice leaders note that some women who would like to have children, or to have more children, are limiting their fertility because of poverty, a condition disproportionately experienced by women of color. These women are "choosing" not to have children, but their choices would be taking place in a different context and might well have different outcomes were they not making their decisions based on economic constraint.

Native American women did not experience the same type of government-sanctioned slavery that African American women did, nor were they routinely forced to bear children to augment white slave owners' holdings.[13] Before and after the Civil War and the abolition of slavery, whites profited mostly not by increasing but rather by decreasing the population of Native Americans, thus gaining access to and claiming ownership of land and resources that had not previously belonged to them. Whites diminished the Native American population through war, disease, relocation, and starvation. In addition, from the late nineteenth century through the early twentieth century many children born to

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[13] I use the term "Native American" in reference to indigenous people of what is now the continental United States. Currently there are 567 federally-recognized tribes and additional groups seeking federal recognition. Here, the term "Native American" is meant to include indigenous people from the full range of tribes and from a variety of geographic, cultural, and linguistic backgrounds.

Native American women were removed from their homes to attend compulsory boarding schools designed to force their assimilation into white society.[317] Typically, children at boarding schools were required to abandon their Native languages, styles of dress, and even names. Although these policies had been relaxed by the peak years of boarding school attendance in the 1970s, the schools continued to immerse children in mainstream American culture.

During (and, based on available data, slightly before and after) the 1970s, when the largest number of Native American children were being raised away from their families and culture, the largest number of Native American women were being sterilized. Between 1968 and 1982, the per capita sterilization rate among Native American women was 42 percent, higher than among any other ethnic group.[318] Poverty forced many Native American women to depend almost entirely upon the federal government's Indian Health Service (IHS) for health care, making them especially vulnerable to government population control efforts.[319] Decades before it was approved for use in the general population, the IHS injected the long-acting contraceptive drug Depo-Provera to hundreds of Native American women, many of them developmentally disabled.[320] In the 1970s, Native American physician Constance Redbird Pinkerton-Uri, after hearing about IHS population control abuses from Native American women, convinced Senator James Abourezk to prompt the federal General Accounting Office (GAO) to investigate such claims. The GAO examined records at four of the twelve IHS hospitals and found that in three years from 1973 to 1976, 3,406

women were sterilized at these facilities. The GAO also found that there were deficiencies in the informed consent process.[321] For example, the consent form did not explain that women had the right to refuse to be sterilized.[322] Although this was a limited study, Senator Abourezk noted that the population of Native American women across the country was small and that 3,406 sterilizations among Native American women would be equivalent to 452,000 sterilizations among white women.[323]

Native Americans were not the only women subject to U.S. colonization who experienced coerced sterilization. Once the U.S. assumed governance of Puerto Rico in 1898, limiting population growth in the territory became a U.S. interest.[324] By the 1930s, instead of providing Puerto Rican women with access to a range of contraceptive options, the U.S. promoted sterilization.[325] Door-to-door campaigns promoting sterilization, along with favoritism on the part of industrial employers towards sterilized women, helped make the procedure so common that it became known simply as “la operacion.”[326] By 1965, one third of all Puerto Rican mothers had been sterilized, a prevalence ten times higher than that in the continental U.S.[327] One 1960s study showed that one out of three sterilized women did not know that the procedure was permanent.[328]

Figure 17: Stop Forced Sterilization[329]

While many women of color, poor women, and disabled women were pressured or even tricked into being sterilized, middle class white women had difficulty obtaining a tubal ligation when they desired one. They were often denied based on a formula put forth by the American College of Obstetricians and Gynecologists, which recommended against performing a tubal ligation as a means of birth control unless the woman's age multiplied by the number of children she had totaled 120, and unless two physicians and a psychiatrist agreed with her decision.[330] Not surprisingly, at a time when other reliable methods of birth control were less plentiful than they are today, many women wanted tubal ligations, and many were denied. In the 1970s, when groups concerned about high sterilization rates among women of color, poor women,

and disabled women advocated tighter restrictions on sterilization, many middle class white women opposed their efforts. Representatives from NARAL and Planned Parenthood, for example, testified against new restrictions, and the American Civil Liberties Union (ACLU) sued hospitals refusing to perform elective sterilizations.[331]

Given the historical reality of medical abuses and even genocide committed against vulnerable groups of people, it is not surprising that some have concerns about policies that may seem to promote death, especially if the decision about who lives or dies is in the hands not of the individual but of "authorities." One lesson of the reproductive justice movement may be that while practices such as pregnancy prevention, abortion, sterilization, and assisted dying might be used to increase individuals' autonomy, they can also be misused by those in power to control populations viewed as undesirable, thus decreasing autonomy and self-determination among individual members of that population. The question of who has the authority to make the final decision is of paramount importance.

Single-Issue Organizing and Meaningful Choice

The reproductive justice framework insists that for the concept of "personal choice" to be meaningful in the abortion decision, a woman must have the choice not only to terminate a pregnancy but also to continue a pregnancy and bear and raise a child (or many children) in a safe, healthy, and culturally appropriate environment. "Choice," then, requires not just the single issue of

having access to an affordable legal abortion. It also requires that a woman have access to conditions that would support her in carrying, delivering and raising her child, such as pre-natal and general health care, a living wage, quality day care, decent schools, a safe environment, and culturally-appropriate community resources, among other things. Critics complain that this agenda includes "everything,"; that reproductive justice, thus framed, cannot be reduced to a "single issue."[332] Despite this critique, the concept of reproductive justice is increasingly put forth by women of color and their allies in a prodigious body of work.[333]

Similarly, for the concept of "choice" to be meaningful in the decision to self-direct one's own dying, an individual must have the choice not only to hasten death but also to prolong life. Access not only to direct health care services (life-prolonging treatments, hospice care, and adequate pain control) but also to other supports is required. These supports might include family-friendly employment policies for care givers; in-home non-medical support for the disabled, ill, or frail elderly; accessible day care centers for the aging; and affordable assisted living facilities.

Inclusive Organizing

At a 1989 conference, "In Defense of Roe," historic because it brought together women of color and white women to engage in a dialog about coalition building in the movement to protect abortion rights, women of color presented a statement that said, in part:

> There is a real need recognized by the people at this conference, and to some extent by the mainstream pro-choice organizations, to broaden the pro-choice constituency. As part of this effort to broaden the base, women of color have been asked to support pro-choice activities . . . Women of color, though they have given their support, have done so with mixed emotions, because they feel quite often that they are being used, not really included into the defining, articulating, and decision-making mechanisms of those organizations.[334]

To stop the continuation of these practices, the women of color in attendance set forth criteria for their participation in future activities, including, "…having been empowered and considered in framing the issues and in setting the agenda, in determining activities—not only called upon to participate at the implementation stage…"[335] They further stated, "Until we focus on quality of life, quality of care, survival and access issues, women of color will not automatically endorse organizations or actions… To implement these goals we want a network of existing women-of-color organizations to set an agenda based on these priorities."[336]

One example of an inclusive reproductive justice agenda was developed by the Native American Women's Health Education Center:

Agenda for Native Women's Reproductive Justice

1. The right to knowledge and education for all family members concerning sexuality and reproduction that is age-, culture-, and gender-appropriate.

2. The right to all reproductive alternatives and the right to choose the size of our families.

3. The right to affordable health care, including safe deliveries within our communities.

4. The right to access safe, free, and/or affordable abortions, regardless of age, with confidentiality and free pre- and post-counseling.

5. The right to active involvement in the development and implementation of policies concerning reproductive issues, which include but are not limited to pharmaceuticals and technology.

6. The right to include domestic violence, sexual assault, and AIDS as reproductive justice issues.

7. The right to programs that meet the nutritional needs of women and families.

8. The right to programs to reduce the rate of infant mortality and high-risk pregnancies.

9. The right to culturally specific comprehensive chemical dependency prenatal programs including, but not limited to, prevention of Fetal Alcohol Syndrome and its effects.

10. The right to stop coerced sterilization.

11. The right to a forum for cultural/spiritual development, culturally-oriented health care, and the right to live as Native women.

12. The right to be fully informed about and to consent to any forms of medical treatment.

13. The right to determine who are members of our Nations.

14. The right to continuous, consistent, and quality health care for Native people.

15. The right to reproductive justice and support for women with disabilities.

16. The right to parent our children in a non-sexist, non-racist environment.

17. The right of Two Spirited women, their partners, and their families to live free from persecution or discrimination based on their sexuality and/or gender, and the right to enjoy the same human,

political, social, legal, economic, religious, tribal and governmental rights and benefits afforded all other Indigenous women.

18. The right to give birth and be attended to in the setting most appropriate, be it home, community, clinic or hospital and to be able to choose the support system for our births, including but not limited to, traditional midwives, families and community members.

19. The right to education and support for breastfeeding that includes but is not limited to individuals and communities that allow for regrowth of traditional nurturing and parenting of our children.

Since the 1989 “In Defense of Roe” conference, a network of women-of-color organizations has influenced the agenda of mainstream reproductive rights organizations. Because many of the practical and legal challenges, conceptual approaches, and strategy questions faced by right-to-die activists were earlier faced by reproductive freedom activists, it is conceivable that veteran reproductive freedom activists may have valuable insights to offer right-to-die organizers. In particular, the reproductive justice model—which acknowledges the dangers of population control, the short-comings of single-issue agendas, and the need for inclusive outreach and organizing strategies—all while holding fast to the principle of promoting and protecting diverse women’s autonomy and self-determination (including access to abortion) may provide a valuable model for the right-to-die movement. The question of whether and how the right-to-die movement will develop inclusive agendas is still open. Insights from veterans of the abortion and reproductive justice movements about how the right-to-die movement might organize inclusively are presented in the following chapter.

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[179] Linda Greenhouse and Reva B. Siegel, *Before Roe V. Wade: Voices That Shaped the Abortion Debate before the Supreme Court's Ruling* (New York: Kaplan Publishing, 2010).

[180] Procon.org, "Euthanasia," http://euthanasia.procon.org/view.resource.php?resourceID=000132.

[181] Greenhouse and Siegel, *Before Roe V. Wade: Voices That Shaped the Abortion Debate before the Supreme Court's Ruling*.

[182] Margaret Pabst Battin, Rosamond Rhodes, and Anita Silvers, eds., *Physician-Assisted Suicide: Expanding the Debate* (New York: Routeledge, 1998).

[183] Baehr, *Abortion without Apology: A Radical History for the 1990s*.

[184] Philip Nitschke and Fiona Stewart, *The Peacful Pill Handbook* (Bellingham: Exit International, 2009).

[185] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 8.

[186] Ibid., 11.

[187] Ibid., 9.

[188] Ibid., 10.

[189] Ibid., 10-13.

[190] Ibid., 114.

[191] Ibid., 14.

[192] Ibid.

[193] Ibid.

[194] Ibid.

[195] Ibid., 14-15.

[196] Nitschke and Stewart, *The Peacful Pill Handbook*, 47-49.

[197] Ibid., 44.

[198] Ibid., 46.

[199] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 12.

[200] Jeff St. Clair and Kevin Niedermier, "Cleveland Billboard Promotes "Death with Dignity"," WSKU, http://wksu.org/news/story/27602.

[201] Oliver, "Addressing Access Barriers to Legal Assisted Dying," 91.

[202] Greenhouse and Siegel, *Before Roe V. Wade: Voices That Shaped the Abortion Debate before the Supreme Court's Ruling*.

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[206] People Magazine, "A Terminal Cancer Patient's Controversial Choice," http://people.com/celebrity/terminally-ill-brittany-maynard-why-im-ending-my-life-in-less-than-three-weeks/.

[207] Patricia Maginnis and Lana Clark Phelan, *The Abortion Handbook for Responsible Women* (North Hollywood: Contact Books, 1969).

[208] Nitschke and Stewart, *The Peacful Pill Handbook*.

[209] Derek Humphry, *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying* (Eugene: Hemlock Society, 1991).

[210] Maginnis and Phelan, *The Abortion Handbook for Responsible Women*, 119-21.

[211] Fox, Kamakahi, and Čapek, *Come Lovely and Soothing Death: The Right to Die Movement in the United States*, xi.

[212] Ian Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America* (New York: Oxford University Press, 2003), 65.

[213] Fox, Kamakahi, and Čapek, *Come Lovely and Soothing Death: The Right to Die Movement in the United States*, xi, 28.

[214] Ibid., 28.

[215] Humphry, *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying*, 13.

[216] Richard Knox, "Judge Dismisses Assisted Suicide Case against Pennsylvania Nurse," *SHOTS: Health News From NPR* (2014), http://www.npr.org/sections/health-shots/2014/02/12/275913772/judge-dismisses-assisted-suicide-case-against-pennsylvania-nurse.

[217] Nitschke and Stewart, *The Peacful Pill Handbook*, 283-84.

[218] Ibid., 282.

[219] Ibid., 278.

[220] Ibid., 278-79.

[221] Laura Kaplan, *The Story of Jane: The Legendary Underground Feminist Abortion Service* (New York: Pantheon Books, 1995).

[222] Greg Bluestein, "Final Exit Network: 4 Members of Assisted Suicide Group Arrested," (2009), http://www.huffingtonpost.com/2009/02/26/final-exit-network-4-memb_n_170371.html.

[223] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 21.

[224] Ibid.

[225] Ibid.

[226] Ibid., 22.

[227] Ibid.

[228] Ibid.

[229] Ibid., 23.

[230] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 24. Reprint of drawing by Suzanne Gage, from Menstrual Extraction brochure distributed by Feminist Women's Health Centers published in *Quest,* vol. 4, no. 3, summer, 1978.

[231] Nitschke and Stewart, *The Peacful Pill Handbook*, 96.

[232] "Doing It with Betty," https://exitinternational.net/product/the-peaceful-pill-ehandbook-ppeh/.

[233] Kaplan, *The Story of Jane: The Legendary Underground Feminist Abortion Service*.

[234] Meredith Stern, "Jane-Underground Abortion Service," http://justseeds.org/product/jane-collective/.

[235] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 27.

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[237] Ibid., 28.

[238] Ibid.

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[243] Ibid., 29.

[244] Cyril Means, Jr., "The Phoenix of Abortional Freedom," *New York Law Forum* 17 (1971): 335-410.

[245] James Mohr, *Abortion in America: The Origins and Evolution of National Policy* (New York: Oxford University Press, 1978).

[246] Loretta J. Ross and Rickie Solinger, *Reproductive Justice: An Introduction* (Oakland: University of California Press, 2017), 24.

[247] Lieberman, *Leaving You: The Cultural Meaning of Suicide,* 15; Minois, *History of Suicide: Voluntary Death in Western Culture,* 31-32.

[248] Szasz, *Fatal Freedom: The Ethics and Politics of Suicide*, 12. For fuller discussions of suicide and Christianity see: (Lieberman. 2003, pp. 10-15); (Minois. 1999, pp. 31-33).

[249] Ibid., x.

[250] Ibid., xiii.

[251] Ibid.

[252] Ibid.

[253] Ibid.

[254] Greenhouse and Siegel, *Before Roe V. Wade: Voices That Shaped the Abortion Debate before the Supreme Court's Ruling*.

[255] Procon.org, "Euthanasia".

[256] In the sense that it required extensive physician engagement and approval and served only a subset of people, the ALI bill was not unlike the current Oregon-model aid in dying laws in the US.

[257] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 3. Drawing by Patricia Maginnis, used with her permission.

[258] Ibid., 7-8.

[259] Ibid., 18.

[260] Ibid., 45. Drawing by Patricia Maginnis, used with her permission.

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[262] Ibid., 125-26.

[263] Brett Harvey, "No More Nice Girls," in *Pleasure and Danger*, ed. Carole Vance (Boston: Routledge and Kegan Paul, 1984), 204.

[264] Kathie Sarachild, "The Power of History," in *Feminist Revolution*, ed. Redstockings of Women's Liberation (New York: Random House, 1975), 13.

[265] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 43.

[266] Ibid.

[267] Ibid.

[268] Ibid.

[269] Ibid.

[270] Ibid.

[271] Ibid.

[272] Lawrence Stevens, "Suicide: A Civil Right," www.antipsychiatry.org/suicide.htm.

[273] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 44.

[274] Ibid.

[275] Ibid., 45.

[276] Ibid.

[277] Ibid., 46.

[278] Ibid.

[279] Ibid., 46-47.

[280] Lucinda Cisler, "On Abortion and Abortion Law: Abortion Law Repeal (Sort of): A Warning to Women," in *Notes from the Second Year: Women's Liberation: Major Writings of the Radical Feminists*, ed. Shulamith Firestone and Anne Koedt (New York: Radical Feminists, 1970), 89-93.

[281] Harvey, "No More Nice Girls."

[282] Guttmacher Institute, "An Overview of Abortion Laws," https://www.guttmacher.org/state-policy/explore/overview-abortion-laws.

[283] Jane Silliman et al., eds., *Undivided Rights: Women of Color Organize for Reproductive Justice* (Cambridge: South End Press, 2004).

[284] Ibid.

[285] Linda Gordon, "Remembering Margaret Sanger's Legacy, 100 Years Later," Organization of American Historians, http://tah.oah.org/november-2014/margaret-sanger/. Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America*, xv.

[286] Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America*, 53.

[287] Ibid., 19.

[288] Joseph Fletcher, "The Patient's Right to Die," *Harper's Magazine* 221 (1960): 143.

[289] Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America*.

[290] William J. Robinson, *Eugenics, Marriage and Birth Control* (New York: The Critic and Guide Company, 1917), 76.

[291] Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America*, 35.

[292] Ross notes in *Undivided Rights*, “Black women in the 1920s and 1930s wanted individual control over fertility, while at the same time they resisted government and privately funded anti-natalist population control campaigns. This dual-value system seeded an expanded version of reproductive freedom that guides our work today.” p. 162.

[293] Maurianne Adams, Lee Ann Bell, and Pat Grifin, *Teaching for Diversity and Social Justice*, 2 ed. (New York: Taylor and Francis, 2007), Appendix 14C.

[294] The Historical Marker Database, "1907 Indiana Eugenics Law," www.hmbd.org/marker.asp?marker=1829.

[295] Adams, Bell, and Grifin, *Teaching for Diversity and Social Justice*.

[296] Ibid.

[297] Ibid.

[298] Adrienne Asch and Michelle Fine, "Shared Dreams: A Left Perspective on Disability Rights and Reproductive Rights," in *From Abortion to Reproductive Freedom: Transforming a Movement*, ed. Marlen Gerber Fried (Boston: South End Press, 1990), 234.

[299] Ibid., 235.

[300] Heyer, "Rejecting Rights: The Disability Critique of Physician Assisted Suicide," 102.

[301] Nancy Mairs, *Waist-High in the World: A Life among the Non-Disabled* (Boston: Beacon Press, 1997), 21.

[302] Heyer, "Rejecting Rights: The Disability Critique of Physician Assisted Suicide," 78.

[303] Ibid., 97.

[304] Rosemarie Garland-Thomson, "The Cultural Logic of Euthanasia: "Sad Fancyings" in Herman Melville's "Bartleby"," *American Literature* 76, no. 4 (2004): 779.

[305] Ibid., 781.

[306] Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America*, 287.

[307] Sherwin Nuland, *How We Die: Reflections on Life's Final Chapter* (New York: Vintage Books, 1995), 259.

[308] Lawrence R. Samuel, *Death, American Style: A Cultural History of Dying in America* (Lanham: Rowman and Littlefield Publishers, Inc., 2013), x.

[309] Ibid., xi.

[310] Loretta Ross, "African-American Women and Abortion," in *Abortion Wars: A Half Century of Struggle, 1950-2000*, ed. Rickie Solinger (Berkeley: University of California Press, 1998), 164-67.

[311] Ibid., 167.

[312] Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 1997), 11.

[313] Ibid., 12.

[314] Ibid., 17.

[315] Ibid., 70.

[316] Frances Beal, "Double Jeopardy: To Be Black and Female," in *Sisterhood Is Powerful: An Anthology of Writings from the Women's Liberation Movement*, ed. Robin Morgan (New York: Random House, 1970).

[317] David Wallace Adams, *Education for Extinction: American Indians and the Boarding School Experience, 1875-1928* (Lawrence: University of Kansas Press, 1995).

[318] D. Marie Ralstin-Lewis, "The Continuing Struggle against Genocide: Indigenous Women's Reproductive Rights," *Wicazo SA Review* 20: 75.2005: 75.

[319] Sally J. Torpy, "Native American Women and Forced Sterilization: On the Trail of Tears in the 1970s," *American Indian Culture and Research Journal* 24, no. 2 (2007): 1.

[320] Ralstin-Lewis, "The Continuing Struggle against Genocide: Indigenous Women's Reproductive Rights," 86.

[321] Ibid., 81.

[322] Ibid.

[323] Torpy, "Native American Women and Forced Sterilization: On the Trail of Tears in the 1970s," 7.

[324] Kathryn Krase, "History of Forced Sterlization and Current U.S. Abuses," www.ourbodiesourselves.org/health-info/forced-sterlization/.

[325] Ibid.

[326] Ibid.

[327] Ibid.

[328] Ibid.

[329] Baehr, *Abortion without Apology: A Radical History for the 1990s*.

[330] Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*, 95.

[331] Ibid., 96.

[332] Ross and Solinger, *Reproductive Justice: An Introduction*, 70.

[333] Ibid., 71.

[334] Lynn Paltrow, "In Defense of Roe," https://vimeo.com/4873057.

[335] Ibid.

[336] Baehr, *Abortion without Apology: A Radical History for the 1990s*, 53.

CHAPTER FOUR

VETERAN REPRODUCTIVE FREEDOM LEADERS' VIEWS ON SELF-DIRECTED DYING

Interviewees

As the preceding chapter shows, there are many similarities between the abortion movement and the right-to-die movement. My goals in interviewing veteran reproductive freedom activists about their thoughts regarding self-directed dying in general and these similarities in particular were:

- To gather feedback from members of the veteran reproductive freedom activist community about 1) whether they agree with my identification and characterization of these similarities, and 2) whether, and in what ways, they see the similarities and differences between issues as relevant to their consideration of the right to die;
- To broaden my own consideration of the right to die by incorporating the perspectives of experienced and widely respected activists from a variety of ethnic, racial, economic, geographic, and experiential backgrounds; and
- To determine whether, and in what ways, veteran reproductive freedom activists in their 60s, 70s, and 80s might be inclined to shape the evolving right-to-die movement.

One thing I have learned in my decades of activism is that just because I view an issue a certain way does not mean that others will see things as I do. Whether the issue I was working on was domestic or sexual violence, LGBTQ oppression, or women's reproductive health, I found that my work was more successful when I sought the input of people who shared my core values regarding feminism and social justice but who also offered wisdom based on their different personal and professional experiences. For this project, I interviewed some women I had turned to for guidance in decades past, some I had heard of and respected but did not know well, and some who were strangers to me but who were recommended by colleagues and/or were affiliated with organizations I appreciated and trusted. Each interviewee is widely respected within various niches of the feminist movement today, each has some avenue for understanding and also for influencing other women's thinking about health issues, and each brings a distinct perspective to issues surrounding assisted death. Their perspectives are shaped by their personal experiences. Their personal experiences, in turn, are shaped in part by their varied cultural, economic, geographic, and racial and ethnic backgrounds. As with so many issues (abortion being only one example), the concept of "the right to die" can be viewed in many different ways depending upon the vantage point of the viewer. The ten interviewees quoted here share a foundation of decades of women's liberation activism. At the same time, they offer ten different vantage points from which to view self-directed dying.

I used information gleaned in these interviews to address the questions above. One unexpected benefit of these interviews was that interviewees brought to my attention additional similarities between self-directed dying and reproductive freedom, especially in regard to present-day restrictions on abortion. These additional similarities are described below. Another unexpected benefit was that, although I had met some of the women before our interviews, I now have a broader network of activists who are familiar with these issues to whom I can turn for input, advice, and possibly even organizing assistance. Interviewees are:

- **Charon Asetoyer,** founder and Executive Director of the Native American Women's Health Education Resource Center (NAWHERC) located on the Yankton Sioux Reservation in Lake Andes, South Dakota. Since its founding in 1988, NAWHERC has become a leading pathfinder in addressing indigenous women's sexual and reproductive health and justice. Asetoyer spearheaded the effort to develop the multi-faceted Native American women's reproductive justice agenda included in the previous chapter. Born in 1951, she works tirelessly on issues including domestic violence and environmental justice. At the time of our interview she was deeply involved in the struggle in Standing Rock, North Dakota, to protect water and Native land threatened by the proposed Dakota Access Pipeline.

- **Rebecca Chalker,** active leader in the feminist women's health movement since its emergence during the second wave of feminism. Chalker is the author of *The Clitoral Truth, The Complete Cervical Cap Guide,* and many other books and articles about women's health and sexuality. She co-edited *A New View of a Woman's Body* and *How to Stay Out of the Gynecologist's Office*, both of which were projects of the Federation of Feminist Women's Health Centers in 1981. With Carol Downer, she co-authored *A Woman's Book of Choices: Abortion, Menstrual Extraction, and RU-486.* Chalker is a white woman in her 70s.

- **Judy Costlow,** retired Health Education Specialist for the State of New Mexico. Costlow was a co-founder in 1974 of the Santa Fe Health Education Project and continues to volunteer as its Special Projects Coordinator. She is co-author of two editions of their book, *Menopause: A Self Care Manual.* She is a white woman in her 70s. Costlow was the primary caregiver for her husband, who in his later years lived with Parkinson's, a non-fatal but progressive neuromuscular disease that causes movement disorders and can lead to impaired cognition. When we spoke, she had recently had a near-death experience and survived months of rehab after a truck drove into a group of bicyclists, killing two people and severely injuring her.

- **Lenore Ku'umeaaloha Gomes,** Director of the University of Hawai'i (UH) Operation Kua'ana, a program to create firm foundations for Native Hawaiian students to succeed at the undergraduate and graduate levels. Since the inception of the UH Women's Center, Gomes has provided technical assistance to that organization, which has addressed issues including reproductive rights, self-help health care, and domestic violence. A Native Hawaiian, Gomes has for decades participated in the Hawaiian Sovereignty movement, including through Na Mamo O Hawai'i, a group dedicated to ensuring that the perspectives of LGBT Hawaiians are incorporated into the Sovereignty movement and that plans for Sovereignty do not replicate the oppression of LGBT people evident in American history. A developer of the inclusive Aelike Model of organizing, she has collaborated to reach out to Sovereignty and other groups to ensure that people who are least empowered but most impacted by decision-making have a voice. In 1970, three years before *Roe v. Wade,* Hawaii became the first state to legalize abortion at the request of any resident pregnant woman, and Gomes had a legal abortion at age 28. Born in 1945 and now 72, she went on to mother many children and young people, including biological offspring, kin, and students.

- **Charlea Massion, M.D.,** who for more than 20 years has co-taught a women's health lecture series at Stanford University's Medical School

which has introduced medical students to the psychological, social, political, cultural, and spiritual aspects of women's health. Massion is a co-founder of the American College of Women's Health Physicians. She has long been an active volunteer with the National Women's Health Network and she co-authored the Network's book *The Truth About Hormone Replacement Therapy*. With Adriane Fugh-Berman, Director of Pharmed Out, she co-authors the "Rx for Change" column in the Network's newsletter. Massion is the Chief Medical Director of the Hospice of Santa Cruz County. She is a white woman in her 60s.

- **Laura Mentch,** long-time activist with feminist women's health centers. After studying health education, Mentch worked in university health and sexuality services and community clinics. She was a founding member of the Mabel Wadsworth Women's Health Center in Bangor, Maine, and also worked at the Portsmouth Feminist Health Center in New Hampshire, both of which are still thriving. For nearly two decades, Mentch also worked at Bridger Clinic in Bozeman, Montana. Mentch lives with Cystic Fibrosis (CF) and was recovering from CF-related surgery when we spoke.[14] She is deeply engaged with the CF

[14] During our interview, Mentch and I spoke about the possible differences between the experiences of people with a visible physical disability, such as someone born with congenital abnormalities in the musculoskeletal system, and

community and is involved in two research projects about health, sexuality, and reproduction for women living with CF. Mentch travels to receive medical care from CF specialists at least quarterly. Her travel and care are supported through her husband's medical insurance plan, her disability benefits, and philanthropic groups that provide assistance to people living with CF. She is a white woman in her 60s.

- **Luz Marina Rodriguez,** key founder of SisterSong Women of Color Reproductive Health Collective and former Executive Director of the Latina Roundtable on Health and Reproductive Rights. Born in 1956 on the Lower East Side ("*Loisaida*") of Manhattan in New York City to parents who had recently arrived from Puerto Rico, Rodriguez frequently served as a caretaker for her mother, who was often ill and

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the experiences of someone with a less visible or sometimes invisible physical disability, such as CF. Interestingly, however, Mentch pointed out that a "wrongful birth" lawsuit brought in our mutual hometown of Bozeman, Montana, illustrated how genetic testing during pregnancy has altered the concept of what abnormalities may be "visible." In *Kerrie Evans v. Peggy Sanson, Dr. William Peters, Park Clinic, and Bozeman OB/GYN,* the mother of an infant born with CF argued that her prenatal care providers had failed to diagnose the fetus as carrying the gene for CF, and that had she known about this abnormality she would have had an abortion.

bedridden, and for her younger brother. In the 1970s, Rodriguez became deeply involved in *Loisida* cultural activities. Growing up, she had heard neighborhood women discuss "*la operacion*," but it was not until college that she researched the history of sterilization and birth control experimentation targeting Puerto Rican women and understood these issues as systematic strategies for population control. Rodriguez has parented many children, including two biological sons, a stepson, a foster daughter, a kinship foster child, and grandchildren. Currently, she shares a home with her husband, who has been diagnosed with Alzheimer's, and she is the primary caregiver for her grandson, who lives with Autism. Now in her early 60s, Rodriguez provides support to nonprofits through her consulting firm, Visionary Allies.

- **Loretta Ross**, co-creator of "Reproductive Justice" practices and theory coined by African American women in 1994. Ross was a co-founder and National Coordinator of SisterSong Women of Color Reproductive Justice Collective from 2007-2012. She co-authored *Undivided Rights: Women of Color Organize for Reproductive Justice* in 2004. With Rickie Solinger, she is the co-author of *Reproductive Justice: An Introduction.* Her next book, *Radical Reproductive Justice*, will be published by Feminist Press in late 2017. A sought-after speaker and author of numerous articles about human rights, violence against women, reproductive justice, and

appropriate whiteness, Ross is an African American woman in her 60s and a tireless activist. When we spoke, her only child had died very unexpectedly five weeks previously.

- **Alice Wolfson,** long-time feminist activist and a pioneer in the women's health movement. Wolfson moved to Washington, D.C., in 1969, where she joined DC Women's Liberation and was a member of the "Daughters of Lilith" collective. She helped organize many actions, including a sit-in in the office of the Secretary of the Department of Health and Human Welfare. Hers was one of the leading voices protesting the deliberate withholding of information about the dangerous side effects of oral contraceptives and the lack of female participation in the 1970 Pill Hearings. Women's actions during the Pill Hearings and their demands for informed consent led to the first wide-scale patient package inserts informing patients of potential side effects of prescription medications. Wolfson was a founding member of the National Women's Health Network and also co-founded the Committee to Defend Reproductive Rights, which fought for and won both California state regulations protecting women against sterilization abuse and court decisions guaranteeing MediCal coverage of abortion. A Jewish woman in her 70s, Wolfson has mothered two sons, one of whom was diagnosed with Leukemia at age 12 and died at age 16.

Today, she remains active as a lawyer fighting for the rights of people with disabilities who have been discriminated against by their insurance companies.

- **Jackie Young,** consultant, speaker, advocate and volunteer for projects and issues that inspire social change and healthy communities. Young holds a Ph.D. in Women's Studies and Communication. She has a history of advocacy on issues relating to discrimination, health, and safety. Her early career in the 1970s was in speech pathology, which led to her advocacy of the deinstitutionalization of children with disabilities. Today, Young serves as Chair of the Hawaii State Judicial Selection Commission, is a member of the Hawaii State Advisory Committee for the U.S. Commission on Civil Rights, a board member of ACLU Hawaii, and is deeply engaged with the American Cancer Society's Hope Lodge Campaign. In addition, she was recently re-appointed to the U.S. Department of Defense Advisory Committee on Women in the Services (DACOWITS). (Young served on DACOWITS from 1994-1997 when women were integrated into combat support roles.) She was elected to the Hawaii State House of Representatives in 1990 and was then elected its first woman vice-speaker in 1992. Young is a founding member of Hale Ola, a spouse abuse shelter in Windward

Oahu. In 2013, she was a delegate to a global conference in Bangkok, Thailand, on Sexual Violence Research Initiatives. She is the mother of four adult children and three grandchildren in college. Her advocacy work and life story have been featured in syndicated newspapers, national magazines and TV specials. Young is a third-generation Korean-American woman in her eighties.

The interviews, most of which took place by phone and all of which were recorded, were structured but open-ended. Prior to every interview I provided each woman with a four-page brochure explaining this research project, highlighting some of the similarities between the abortion movement and the right-to-die movement, and presenting a list of 16 questions. (Appendix A.) The questions were:

- In what ways, if any, do you consider dying to be a “women’s issue,” and in what ways, if any, do you not consider it to be a "women’s issue?”
- In what ways is the issue of controlling whether, when, and how you reproduce similar to the issue of controlling when and how you die, and in what ways is it different?
- What conditions are necessary for the concept of “choice” to be truly meaningful in self-directed dying?
- What do you think about the fact that people who want assistance in hastening death sometimes travel or move to get the services they seek?
- What do you think about the fact that people who want assistance hastening their own death sometimes resort to subterfuge?
- What should be the requirements for receiving aid in dying?

- Who should, and who should not, be prevented from hastening his or her own death?
- Who should be able to assist those who want to hasten death?
- What might be the dangers, and what might be the advantages, of involving doctors in providing (or denying) aid in dying?
- What good things, and what bad things, might happen if “peaceful pills” (drugs to bring about a peaceful death) were available without prescriptions?
- What laws, if any, should regulate assisted suicide?
- What do you think about the idea that death might sometimes be seen not as something that *happens to you* but as something you *do, a final, culminating activity?*
- What do you think about the idea of reconceiving suicide as a civil right?
- In what ways, and to what extent, are issues related to self-directed dying priorities for the people you know?
- Who needs to be at the table to ensure that the right-to-die agenda going forward increases the well-being of all people (or at a minimum does not decrease the well-being of any people)?
- What other questions need to be asked?

I knew little or, most often, nothing about these women’s opinions on self-directed dying when I approached them. The women were asked to address any of the questions that interested them and also to raise additional issues. Interviews drew on an oral history approach; each woman was encouraged to talk about experiences in her own personal or professional life that she believed shaped her thinking about self-directed dying. Interviewees talked about their

experiences with illegal abortions, cancer scares and cancer treatments, depression, suicidal ideations, the deaths of loved ones, and their professional experiences as caregivers or organizers, among other topics. I used the information women provided in these interviews to try to answer the two research questions I had posed at the outset of this project:

- How might, or might not, highlighting the parallels between the struggle for abortion and the struggle for self-directed dying draw support from Baby Boomer veterans of the reproductive rights movement for the right-to-die movement?
- How might the lessons of the reproductive freedom movement inform the right-to-die movement?

Below I describe five themes relevant to the first question that emerged during the interviews and two themes relevant to the second question. I also describe three additional themes related specifically to self-directed dying.

Five Themes Relevant to How Highlighting the Parallels between the Struggle for Abortion and the Struggle for Self-Directed Dying Might, or Might Not, Draw Support from Baby Boomer Veterans of the Reproductive Rights Movement for the Right-to-Die Movement

In terms of whether, and how, highlighting parallels between the struggle for abortion and the struggle for self-directed dying might draw support from Baby Boomer veterans of the reproductive rights movement for the right-to-die

movement, five themes emerged from the interviews. Veteran reproductive freedom activists:

1. Had had direct experience with end-of-life issues;
2. Did not generally view dying as a “women’s issue”;
3. Shared a core commitment to people’s ability to control their own bodies;
4. Recognized that making a practice illegal did not prevent it; and
5. Understood that making a practice legal did not necessarily make it accessible.

First, veteran reproductive freedom activists had had direct experience with end-of-life issues. All ten interviewees had had enough direct experience with their own illnesses and with the illnesses and deaths of family members, friends, and patients that they did not need a proxy issue, such as abortion, to start them thinking about end-of-life issues. In fact, most women began their interviews by talking about personal life experiences that had made them consider end-of-life issues, often including self-directed dying. For example, Becky Chalker explained, “I’ve sort of been pushed to think about it because I have a friend who is also 73—we were born just a few months apart—who was diagnosed about three years ago with uterine cancer.” Becky’s friend asked her doctors, “What happens if the worst comes?” Aid in dying was not legal in her state, and her doctors’ answers were not explicit, but Chalker’s friend left the conversation believing that her doctors would supply her with drugs sufficient to

hasten her own death if her cancer could not be treated. “She’s cancer-free for three years,” Becky reported. “But she’s faced it. And that’s kind of given me a model . . . .”

Judy Costlow recalled, “My husband got Parkinson’s. And I know that the last year and a half when he was alive he was miserable. I would have loved to have made it easier for him.” Costlow was a member of Compassion and Choices, but aid in dying was not legal in her state. Her husband was in a nursing home and could no longer communicate. “So,” she said, “there wasn’t really any way.” She described her husband as someone who had been very physically active and “loving life” and explained how difficult it was for him to be so disabled and to know that there would be no cure in his future, only further deterioration. She said, “I was really glad that he only lasted as long as he did, because I just think life would have gotten more miserable and more miserable, and almost no matter how much you are surrounded by people who care about you, it’s still really hard.”

Ku’umeaaloha Gomes talked about the events and her feelings at the death of her long-term partner, also Hawaiian, with whom she was raising a child. She reported that at two medical facilities where her partner had received treatment, Gomes suspected that her partner may have been stereotyped and treated without due respect and care. At the Queen’s Medical Center, founded in 1859 by Queen Emma and King Kamehameha IV for the benefit of the people of Hawaii, on the other hand, she feels that she and her partner and their extended

family members were treated respectfully and received excellent care. Believing that it is what her partner would have wanted, Gomes made the difficult decision to turn off life support. She recalled that some people on her partner's side of the family did not agree with her decision, and she stressed the importance of talking about end-of-life wishes with family members and close others. Gomes also discussed the importance of community at the end of life and described the caresses, massages, and songs she, her daughter, and women in the LGBT community offered her partner in her last moments.

Jackie Young discussed insights she gained about living and dying from watching friends struggle with disabilities and diseases and described how they informed her thinking about her own death. She was especially moved by the example of her friend Peggy Chun, a painter who had ALS and began losing control of her muscles when she was in her forties. As the ALS seemed to creep up her body, Chun lost the use of her hands and began painting with her paint brush in her mouth. When that was no longer possible, she continued to work, teaching children to paint murals by directing them with her eyes. Young noted that, perhaps because she was a gifted artist, perhaps because she was widely known as a fun and inspiring person, Chun enjoyed an unusual level of support; a group of people who came to be known as "Peg's Legs" eventually grew to over 100 individuals who shared caregiving responsibilities.[337] Young saw Chun as an example of "not giving up too early," and stated, "Had she taken the 'death pill' earlier her work would not have inspired so many people." What was most

important to Young was that Chun was “useful” and “stayed herself up until the very end.” In light of this, regarding her own thoughts about self-directed dying, Young said:

> I’m 82… Certainly, personally, I feel that if I have dementia—and I’ve seen people in severe stages of dementia—then I’m losing myself, and that’s my reference point. I’m losing who I am as a person and that’s when I would like to check out. Because I’m losing myself. Peggy didn’t lose that. Peggy kept every bit of herself until the very end. Her spirit and her personality and her talent were there until the very end… A lot of people don’t give a lot of thought about that, about what is your drop-off point. At what point do you decide that it’s not useful for you to live on? To me, part of who you are is your experience… I think about life as relationships, and I think when you have dementia you lose your relationships… If you lose how you are related to other people, I think that’s the cut-off, when you lose that humanness of relationships… I would want compression of morbidity. And I have told my children.

Alice Wolfson stated that she was “totally in favor” of physician aid in dying and had been “anxiously looking at what California passed.” She explained that she was quite familiar with the California End of Life Options Act in part because, at the time it was being debated, a dear friend of hers was dying of lymphoma, and she hoped it would become an option for him if he so chose. Wolfson described the Act as “a start” but said it was “not great.” She felt that there were too many requirements and that the need for a terminal diagnosis, the waiting periods, and the mandatory multiple requests made the process “too involved,” “too complicated.” “You should be able to say, ‘I want to die, that’s my right.’” She said, “I don’t know how I would design a law but I certainly know that I would not make you have to jump through hoops to get the prescription.” Wolfson

concluded, “It’s kind of like before abortion was really legal and you had to get a doctor’s note to say you were going to kill yourself; it’s the same thing.”

Second, veteran reproductive freedom activists did not generally view dying as a women’s issue, although interviewees acknowledged that end-of-life experiences are affected by gender. As Wolfson said, “I don’t think of it as a women’s issue, I think of it as a human issue. I think abortion is a human issue, too, but in a different way.” Massion, however, said:

> Dying is both a women’s and men’s issue, and unfortunately some kids’. The way that I sort of see dying or the right to die as a women’s issue is that we see and we know that most end-of-life care is provided by women. These are family caregivers, friend caregivers, or hired caregivers. Most are women. So I think with the right-to-die option, for some families. . . say somebody qualifies, they have the medication, they end their life, that’s going to foreshorten the period of time when that person would have most likely have needed more and more care at home, and for the caregivers to witness more and more either suffering or debility. . . if their symptoms are well managed maybe it will be a stretch of time where they’re mostly sleeping but . . . they aren’t able to do anything for themselves. I think that sort of makes dying, in a certain way, a women’s issue more than a men’s issue.

While statistics confirm Massion’s observations across the population as a whole, Charon Asetoyer, an enrolled member of the Comanche Nation, said that in her community caregiving is gendered in a somewhat different way. She explained that while much of the work of caregiving falls to women, there are many male caregivers, men in the household share responsibility for caregiving, and the work of caregiving is not frowned upon or regarded as women’s work. In fact, young men often care for male elders. When death occurs, a man is typically dressed for his journey by other men, and a woman is dressed by other

women, often by the same women who had participated in her ceremony of becoming a woman. Asetoyer also explained that while married women might indeed be preceded in death by their husbands, they are not necessarily left without caregivers, because in her community kinship networks are extensive and widowed elders are very often cared for by immediate or extended family members. Like other interviewees, she regarded dying as a human issue.

Third, veteran reproductive freedom activists shared a core commitment to people's ability to control their own bodies. Interviewees' insistence on the importance of one's ability to control, as possible and as desired, what happens to one's own body, was a fundamental shared value that they related to both abortion and self-directed dying. For example, below is an excerpt from my conversation with Wolfson:

> Baehr: When I say, "We would never put up with, or would fight against, these kinds of restrictions [waiting periods, consent of multiple physicians, etc.] on abortion," people say, "Well, they're not the same issues."
>
> Wolfson: They are the same in that you have a right to control your own body. I think there is a reason why the right-to-die movement is now happening in an open way, and I do think it's because of the women's health movement for sure and all of the movements toward taking control of your body and the idea that you can control your body.

As another example, below is an excerpt from my conversation with Ross:

> Baehr: What similarities, if any, do you see between abortion and assisted suicide?
>
> Ross: One commonality between abortion and physician-assisted suicide is the question of who gets to decide. And I certainly think that with abortion rights, women should decide – and I don't even go to women and the doctor, I go to women, and then your doctor

> may advise, but not necessarily decide. There's that, because that is the key question – who gets to decide the conditions of their life, or their death? I think focusing on women's autonomy is bedrock. That's what we should always do when it seems morally ambiguous or things become confusing. I always rely on whether or not it impacts a woman's autonomy and her ability to make decisions for herself. Obviously I'm not speaking to men who seek assisted suicide, but I think the question of individual autonomy is the same for men as it is for women.

Fourth, veteran reproductive freedom activists recognized that making a practice illegal did not prevent it. They understood that whether the issue is abortion or hastening one's own death, people will often try to do what they feel they need to do, even when it isn't legal. When asked to describe any similarities she saw between abortion and self-directed dying, Ross further answered by asking, "What are the legal constraints?" and explained, "Obviously if you live in a state where abortion is strictly prohibited or assisted suicide is strictly prohibited, then that's going to have an impact on your decision as well." Then she continued, "But I tend to find, and I think history has proven this out, that with abortions women don't necessarily care about the legal restrictions. They're going to take care of business. They're going to do whatever they think makes sense for them with whatever technology or knowledge is available." She concluded by saying, ". . . I would suspect that physician-assisted suicide or independent suicide, it would be the same. But that's not going to be the primary consideration people account for when they're making decisions about how they live, or end, their lives."

Costlow and Mentch both told me that they had friends who were hiding drugs “just in case.” Wolfson said that, on a visit to Mexico, she had tried to purchase a drug that could hasten death. She explained, “ . . . my friend said, ‘Go in and get cyanide; they have it over the counter.’ You know what? They didn’t! And they thought I was crazy!” “You went and tried?” I asked. “Yes,” she said, “I did! Just to have, you know, just to know it’s there. Just to keep . . . “

Massion, who serves as Chief Medical Director of a hospice, described an event that took place before aid in dying became legal in California. A hospice worker arrived at the home of a client to find a note on the door saying, “Call the police.” She did, and when the police arrived they found the body of their patent with the head covered by a bag. Massion recalled that there was evidence that someone had assisted the woman in hastening death, and she believed that a canister of an inert gas such as helium or nitrogen was part of this evidence. She reported that hospice staff and the oncologist who had been working with this patient were traumatized. They realized that this woman, with whom they had assumed they had a trusting relationship, had been hiding her plans from them, deceiving them. Massion acknowledged that, because California had not yet legalized aid in dying, the patient probably felt she had few choices. She said that the isolation in which she imagined the patient had made her decision, and the presence of a bag

over the body's head, made this event feel more like a suicide (with the term's negative connotations) than like a peaceful assisted death.

Fifth, veteran reproductive freedom activists understood that making a practice legal did not necessarily make it accessible. They believed that whether the procedure in question is abortion or aid in dying, legalization might not make it affordable or even available. The access barriers to abortion have been a topic of public debate for decades. Similar barriers may exist for people attempting to access legal aid in dying. For example, in Santa Cruz, where Massion provides hospice care, many of the local health care institutions are associated with the Catholic Church, which opposes both abortion and physician aid in dying. Doctors affiliated with those institutions are not allowed to provide assistance. Many other doctors remain hesitant to prescribe lethal drugs because of personal beliefs, lack of training, or other reasons. For instance, Massion, who supports legal aid in dying, helped develop a policy at her hospice that its physicians would not prescribe such drugs. Many people still view hospice with fear, and Massion and others were concerned that allowing their physicians to prescribe lethal doses of medication would increase this fear and prevent dying patients from receiving the many important services hospices offer. Massion explained that finding a doctor who might be willing to serve as a prescribing physician, and another who might be willing to serve as a consulting physician, could be difficult. Even when a patient found such doctors, seeing them might involve having to make multiple trips of fairly long distances, something that many terminally ill

patients cannot do. Few of those doctors are willing to make house calls that require hours of travel. Furthermore, once a patient obtains a prescription, the cost of the drug can be prohibitive for some. The price of Seconal, which was very modest for decades, increased to thousands of dollars when aid in dying became legal in California and the pharmaceutical company that owned it saw a possibility for profit.[338] Insurance companies generally do not cover drugs prescribed to hasten death. For some people, the lack of availability and affordability of aid in dying render its legality nearly moot.

Two Lessons Learned from the Reproductive Justice Movement

In terms of how the lessons of the reproductive freedom movement—and especially the reproductive justice movement—might inform the right-to-die movement, two themes emerged:

1. Any medical advance, including those that might increase the well-being of the privileged, once institutionalized, can be weaponized against the less privileged; and
2. Autonomy may mean different things to different people and may be culturally influenced.

Regarding the first theme, Asetoyer acknowledged that the history of genocide, sterilization abuse, and dependence on IHS might well raise concerns about physician aid in dying for Native Americans. Rodriguez said that such concerns had occurred to her, too. Ross stated, “Well of course the problem with

living in a white supremacist, racist, sexist, homophobic, ableist – you know the litany – society is that every legal and technological, scientific advance takes place in that context." She argued that even things that look benign can be abused, ". . . because we have not changed the context in which these things take place. That pretty much is inevitable." She continued, "I mean, we've watched this with every contraceptive advance that we would celebrate as women would turn around and get abused when it came to poor women and women in developing countries." She conjectured that there's no way to escape abuse, ". . . because we have not changed the context in which such abuse takes place. So we have to be wary of that…"

Nonetheless, Reproductive Justice activists interviewed did not oppose but in fact often approved of legalizing aid in dying. Rodriguez said, "Ultimately what Reproductive Justice is really about to me is sovereignty over one's life, body and mind. . ." "People of color. . .", she said, "lost sovereignty over our land, in many cases our language, our culture, our lives. The buck stops here. You cannot have sovereignty over my body." Gomes, a Native Hawaiian Sovereignty proponent, said, "My body is MY body, my decisions are MY decisions."

Regarding the second theme, Ross explained, "The whole question of autonomy is even culturally determined. I mean, just speaking in a narrow way as a person of African descent, we have the philosophical basis of Ubuntu, and so *I am because my community is." "*I could never consider making an end-of-life decision outside of the context of the impact this would have on my community,

my family,… that would be an insult to my ancestors, it would have real spiritual consequences for me…" she explained. Ross continued:

> I think we would agree, cross-culturally, that *who* decides is the ultimate question; what differs is *why* they decide what they do, that's what's culturally determined… What informs that decision is what would definitely change per culture, and I think the Western philosophical decision-making is more of an alienation, so that the person making the decision is less dependent and less reliant on other influences that affect that decision, whereas in some cultures the embeddedness of the individual means that all of these tentacles of relationships have to be taken into account to inform the decision. That doesn't change who the ultimate decision-maker is, but it does change the considerations they have to engage in in order to make the decision.

Asetoyer and I had the following exchange:

> Asetoyer: We have a different outlook on life… the Creator's going to take me when he's good and ready, and I've just never met an Indian person who wanted euthanasia… No, no, never.
>
> Baehr: So it sounds like it's definitely not a priority issue either way. It doesn't sound like there are large numbers of Native people who are going to try to legalize this, and on the other hand it doesn't sound like there are large numbers of Native people who would be really mobilized against legalization. They just sort of wouldn't even use it, probably.
>
> Asetoyer: Yeah, probably, yeah. I mean, I can't say everybody wouldn't, but I just never met anybody that would… A lot of elders, you know, they say that when the elder wants to check out, they just check out. They just turn over and face the wall and that's it, they're gone. They have that understanding of life and death and that's it, they're gone. I've seen it happen… I think everybody has that power, but a lot of people, a lot of cultures, don't embrace it and stop practicing it. So people have lost that control.

Gomes, who spoke in the context of being a Hawaiian in a homeland illegally occupied by America, said:

> I think in America, Americans think really differently about sex and dying. They criminalize sex in so many different ways; you're not

> free, you're not free to talk about it. And I feel the same way about dying. Dying is a natural process. For me, as a Hawaiian person, culturally, in my community, dying is something that we look forward to, because as you age, and when you die, that step is to become *amakua,* to become spiritual advisors—you become that spiritual entity to those you leave behind. Nothing should legislate what happens. It's a beautiful process. And we should be allowed to go out the way that we want to go out. . . People should be empowered to make choices, and their choices should not be limited.

Gomes did not feel comfortable making specific recommendations for aid-in-dying statutes, in part because she did not believe she had enough information about the issue. In conveying her thoughts about natural processes, and attempts to legislate them, she introduced taro plants as a metaphor. Called *kalo* in Hawaiian, taro plants are sacred and central to the Hawaiian creation story. The corm of the taro plant gives rise to suckers, and when the original plant dies, a generation of new plants continues. Gomes presented the life cycle of the taro plant as an illustration of growing and dying as natural processes. She said, "Somehow, for me, in America, that part is missing, that acknowledgement of that natural process. When anything is legislated, it's an attempt to control, to control people's processes. That's not where the answer is; the answer is in people's choices…" She continued:

> One of the things I learned from (my partner's) death is that the person who is dying does not want the family to be in pain and to have to suffer through the process. It should be a beautiful process of allowing the person to pass on to the next level. If that person choses to do it with medication then that's their choice, and they should be allowed to do that. They should be allowed to have different choices on how they do it. It's a natural stage of

> evolvement to a higher stage of being. People should have as many choices as they can have, as many alternatives as they can have, to make their decision.

Three Additional Considerations

Three additional themes related specifically to self-directed dying emerged from the interviews.

1. The trade-offs involved in doctors serving as the only gateway to "peaceful pills";
2. Use of the word "suicide"; and
3. Interviewee differences in prioritizing active aid in dying as an issue but commonalities in prioritizing a broader spectrum of end-of-life issues, especially caregiving options.

In terms of the first theme, the role of physicians in assisted suicide, Wolfson said, " . . . there's still a paternalistic thing that doctors have around their patients . . . I think if you want to be able to get a prescription, you ought to be able to."

Costlow told me:

> I would like to not necessarily go to a doctor. I'd like to get what I needed. Maybe there could be a group that dispenses it, and not necessarily a medical group but counselors, or somebody, that really would listen to you and then could say, "OK, here it is." I sure would like to know that I could get something if and when I needed it through a doctor or through something else, probably through something else.

Mentch said that although she believed assisted dying should be legal, and should not be limited only to people with a terminal illness, she had

concerns about doctors as gatekeepers because of her critique of the medical model's casting of doctors in that role. She explained, "People put the white coats on and say, 'Now I want to be in charge of your birthing, your abortion, your pregnancy decisions as well as your dying decisions." She went on, "It's been medicalized, as birth and abortion care and all women's health became medicalized." Arguing that much of the "soul and spirit" of care was lost when men took over medicine from women, she suggested that, just as women have fought to create birth centers where women can have more say about the birthing experience, we might consider creating what she called "that lovely support network and place to be" for dying. Drawing on her history of working with communities of women to provide care, Mentch wondered whether lay people might not be able to serve as what she called "midwives for death."

Massion said that she saw a potential downside to widespread acceptance of physician aid in dying in the possibility that it might be yet another avenue to over-medicalizing death. She explained, "There could be some underlying current, some pressure, sort of like a C-section, to say, 'I want to choose the time and place that my baby is born, so I'm going to set up a C-section.'" She said this could be a further disconnect from the idea that it is OK to trust your body. Noting that trusting the body is something she discusses with dying patients, Massion explained that she frequently says:

> Your body knows what to do and it's going to wrap things up in an orderly physiological way, and we, hospice, we are going to be here

> to take care of all your symptoms, and help you be as comfortable as possible, but your body will be going through this process and knows what to do, and you can trust that. Trust the natural process of dying.

In spite of their misgivings about relying on doctors to be the source of aid in dying, it was difficult to envision ways to make “peaceful pills” available without having to secure a prescription from a doctor. The possibility of making them available as “over the counter” drugs raised serious concerns about their possible use for impulsive suicide or even murder.

Regarding impulsive suicide, Wolfson said, “It scares me, I have to say.” “I don’t really see choosing not to live through the extremis of a fatal illness, or even an illness in which the treatment is so completely awful – maybe you’ll live at the end of it, but you’re going to suffer for a very long time. It’s a different thing.” She explained:

> I have had clients who have been in major depression, OK? And they don’t start out wanting to kill themselves. They end up wanting to kill themselves. This drug doesn’t work, and that drug doesn’t work, and they just can’t get out of it, OK? That to me is an illness. That’s not the same as you get dumped by your boyfriend and the first thing you do is reach for the drug to kill yourself. That I would want some protection against!

Similarly, Massion cited studies showing that people who attempt suicide but live are often glad that they did not succeed in ending their lives. As a medical professional, she has knowledge and experience that lead her to believe very firmly that protecting acutely suicidal individuals from harming themselves, and supporting them in exploring other options, can help them get through the crisis and go on to reevaluate and recommit to their lives.

Massion sees some type of evaluation when end-of-life decisions are being made as appropriate and advisable, whether that evaluation is provided by a doctor, an advanced care nurse, a mental health care professional, or some other trained practitioner.

Chalker pointed out that ready access not only to drugs but even to information about other mechanisms to reliably bring about a relatively peaceful death carried a risk. A friend of hers who was emotionally troubled but not terminally ill had used information presented in Derek Humphry's book *Final Exit* to commit suicide, an experience which Chalker and other close friends found extremely painful. In spite of this, Chalker did not believe that such information should be prohibited.[339]

Regarding the possibility that accessible "peaceful pills" could be used to commit murder, Costlow said that she could imagine a rare instance in which an overwhelmed caregiver might give such drugs to an ailing person without his or her knowledge or consent. She also stated that publicity around such a case, if discovered, would surely increase public fear of medical aid in dying. Rodriguez said that, should she ever choose to obtain aid in dying, she would likely prefer a non-medical setting so that she could have more say over the time and place and circumstances of her death, but that she thought the involvement in some way of several people, including a physician, would help ensure that people were not coerced into choosing a hastened death. Ross said that she could easily envision "peaceful pills" making domestic

violence even more deadly, explaining, “Powerful narcotics – you really don’t want a black market on those, or you’d see the murder rate spike. So what might benefit those people who wanted assisted suicide might fail to benefit those who didn’t.” Ross hypothesized that making “peaceful pills” widely available would be “really problematic,” saying, “ . . . the amount of women who are murdered by their partners is, of course, one of the major reasons women die. And if they were able to fairly randomly obtain, even on a black market, those kinds of drugs, we would have an epidemic of violence against women.” She stated that making “peaceful pills” widely available was an idea that concerned and alarmed her, concluding:

> It’s not like RU486 and the abortion pill, and there was an underground market for that, and I don’t think you can compare it to that. Making those narcotics available through an underground system, it seems like it would be a short-term solution with really damaging long-term consequences.

The second theme had to do with terminology, specifically the use of the word “suicide.” Among most of the women I interviewed, as in society at large, the word “suicide” carried a profound stigma. The choice of whether or not to describe an act as “suicide,” however, seemed to be influenced not simply by whether the person committing this act was, in fact, bringing about or hastening his or her own death, but by whether or not the person speaking understood or approved of the actor’s act.

Rejecting the term “suicide” might be logical in the case of a terminally ill person whose death was imminent with or without intervention. It might not be

logical in the case of a person without a terminal illness deciding to die because of another type of unbearable suffering, such as intractable depression or a quality of life that he or she found unacceptable. Many interviewees believed that people experiencing at least some forms of non-terminal but unbearable suffering should be able to receive assistance in hastening their own death, and they did not consider this to be suicide. As one woman said, “I don’t see that as committing suicide, I see that as choosing not to suffer.” Another woman, who did not oppose legal medical aid in dying for the terminally ill, stated, “Suicide is never OK.”

Only one woman suggested that suicide – the act or the word – should be de-stigmatized. Most seemed to accept that, by definition, suicide was a negative. Although some women believed that the act of bringing about one’s own death was understandable and permissible in certain situations, even when the person in question was not terminally ill, they did not have a common word to describe this act that did not carry stigma. There does not seem to be a word that, like “suicide,” means that a person brings about his or her own death, but that, unlike “suicide,” carries a neutral or even positive connotation.

Laura Mentch, on the other hand, objected not to the word “suicide” but to the word “commit” in the phrase “commit suicide.”

> You can commit robbery, you can commit murder, so “commit suicide,” makes it sound like a crime. . . And people have such reactions to it. I have known people who have killed themselves, and people go, “Oh, that’s so selfish.” But I think the despair must have been so significant. . . . This whole concept of someone’s personal struggle, a personal situation, that there’s so much public

> condemnation about—*The Girls Who Went Away,* the person who killed themselves. . . these are really deeply personal things that happen to lots of people.[15]

A final theme that emerged in the interviews was that while increasing access to ways to hasten one's own death was a priority issue for some women and not for others, all the women interviewed considered at least some issues related to the end of life to be important concerns.

How highly women prioritize the specific issue of assisted dying may correlate somewhat with their relative level of privilege and with their cultural background. As Ross explained, "When you live a marginalized life, the struggle isn't how to die but how to stay alive. You're really talking about a huge paradigm shift!"

Many of the women I spoke with, however, brought up other issues related to the end of life. Most agreed that we should plan for, and talk with loved ones about, our own deaths much more than we do. For example, Costlow said, "I remember one friend, her husband just died in February (2016). He was in his 80s and she's in her late 70s and I would say, 'Oh, yeah, my husband and I went and updated our will,' or whatever and she would say, 'I don't want to hear about it.'" Costlow continued that when her friend's husband died, the friend said, "Oh

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[15] *The Girls Who Went Away* is the title of a book by Anne Fessler about unwed (mostly white) pregnant girls and women who "went away" to homes for unwed mothers and surrendered their babies for adoption.

my gosh, we haven't done any of this stuff." Costlow concluded, "You've got to think about it, and in our society we don't like to."

Loretta Ross said, "I know that when my mother passed she had a "Do Not Resuscitate" order, and that was a family conversation and fortunately we were all in agreement because she had been in a coma for three years." She said that her mother was ready to go, and it would have been "the height of selfishness" to keep her around on all kinds of life support machines just because her children couldn't let go. She added that the experience had changed her perspective on DNRs and "when you get to say you're through with life." She has since added a codicil to her will and made sure that her DNR is attached. Ross noted that there was a difference between physician-assisted dying and a Do Not Resuscitate order where, without intervention, the end of life would happen anyway; in the case of her mother the health care providers literally just had to turn off the breathing machine and the feeding tubes and all the things that artificially kept her alive. She pointed out, "That's very different than a doctor administering a drug to necessarily terminate a life, but I think there's still… I just relate it in terms of, where does the person's autonomy and decision-making take force, and when does that get overruled by outside forces?"

Ross said that she had had a conversation with her only child, her son, about what her wishes were for the end of her life. Unfortunately, she said, she had not talked with him about his wishes. Very unexpectedly, Ross's son

suffered a massive heart attack five weeks before our interview. She wondered whether her own experience of having to make decisions in the wake of his sudden medical emergency and death might have been less difficult if she had been clearer about his wishes.

Charon Asetoyer said that on her reservation most people want and expect individuals at the end of life to be cared for and to die at home. This is not always possible, however, because Native families on reservations typically live in HUD housing that is small, over-crowded, and not equipped to sufficiently accommodate the needs of a person at the end of life and his or her caregivers. She was saddened to report that the housing shortage on reservations and the lack of home health care services in rural areas pushed many members of her community into nursing homes. “We have no services out in rural areas, out on the reservation, so it is very, very, very difficult,” she explained. “When you’re out in rural America,” she continued, “I don’t care what color you are, (services) are very limited, and then when you’re on a reservation, they’re even more limited.” Asetoyer went on, “If you talk to anybody who has ever taken care of an elder at home they’ll tell you how frustrating it is trying to get someone to stay with your elder while you go to work. When there’s nobody else around, even to hire somebody, it’s very limited, and so we’ve got to look at that.” About caregiving, Asetyer said:

> That’s a really honorable job to have, and there’s just not enough people doing it because there’s not enough federal support, and on and on and on. And people don’t look at it as important, and it is important… It’s a very difficult, difficult situation, and you’re made to

> feel like you are a burden. And that's the last thing that our elders are, are burdens, because that's where our knowledge comes from, that's where our traditions come from. That's the last thing we ever want to do is make an elder feel like they're a burden.

Luz Rodriguez reported that families in her Puerto Rican community typically try to work out ways to care for elders and others in need of support within their extended family networks. To some extent, this is due to the lack of culturally appropriate long-term care facilities and nursing homes. She explained, "They don't have our food and our music, they don't play the same kind of dominoes… our elders decline really quickly in that setting, because community is very important at that stage of life, it keeps people alive, and if you don't have that community you can't thrive."

Judy Costlow, too, discussed the importance of caregiving options as a factor in the quality of life for both the caregivers and those being cared for. She reported that she and her husband were fortunate to live in a retirement community where Costlow could care for him in their apartment. After his Parkison's progressed to the point that he began having dangerous accidents that resulted in broken bones, they decided that he would move into the 24-hour-care facility on the property. Costlow was still easily able to be with her husband every day, taking him out in his wheelchair and bringing him home to have dinner or watch TV in their apartment from time to time. Had he been moved to a facility far away, these daily interactions would have been difficult if not impossible.

Loretta Ross suggested that while the specific issue of hastening one's own death might not lend itself to cross-cultural and cross-class organizing or "gain much traction in communities of color," caregiving was:

> . . . a very salient issue in communities of color because we have the extended kinship networks organically that end up with us doing a lot of kin caring, and it's not always filial relationships, it's our whole network of relationships because of the ways we tend to exist and take in kids and have extended families quite organically. And so that does extend to end-of-life issues. I would think that if there were bridges to be built or common ground to be sought it would probably be in the caregiving area of the movement.

Synthesis

My findings have led me to an observation about how interviewees view the similarities and differences between abortion and self-directed dying and to a tentative conclusion about one way that veteran reproductive freedom activists might shape the evolving right-to-die movement:

1. Observation: While interviewees see some similarities between the movements for abortion and self-directed dying, they also see the issues as different and are more willing to limit personal autonomy in the case of hastening one's own death than in the case of having an abortion.
2. Tentative Conclusion: Highlighting parallels between abortion and self-directed dying may not be an effective way to increase veteran reproductive freedom activists' support for the right-to-die, but lessons learned by the reproductive freedom movement about the

limitations of single-issue agendas and the importance of inclusive organizing could be applied to the right-to-die movement.

Observation: Movement Similarities, Issue Differences

Seeing parallels in the abortion and right-to-die *situations* and *movements* seemed not to translate into seeing the two *issues* as especially similar, at least among most of the women I interviewed. Interviewees did share a core commitment to women's, and people's, ability to determine the course of their own lives, and, to some extent, their deaths, as they saw fit. I was surprised, however, by how little most women viewed the two issues as related, and by how much most favored some form of gatekeeping or other limits on individual autonomy in regard to self-directed dying.[16]

Interestingly, conversations with interviewees helped me add to my list of parallels between the movements because interviewees themselves brought up ways in which the abortion situation today, as opposed to pre-*Roe v. Wade*, resembled the assisted dying situation in terms of referrals, travel, "How To"

[16] As noted above, Alice Wolfson, Loretta Ross, and Laura Mentch mentioned similarities between abortion and self-directed dying, but only one woman indicated that reviewing the parallels between abortion and self-directed dying caused her to think about self-directed dying in a new way. Luz Rodriguez said, "I had not thought about it, had not considered it, until I read your materials, and then it made total sense."

handbooks or other underground sources of information, self-help groups, therapeutic committees, and inclusive organizing strategies. Below, I review the similarities I had presented to each woman prior to our interview, describe how some of the themes raised by interviewees about the abortion situation today have added to the growing list of similarities, suggest how these circumstances limit or support personal autonomy in relation to abortion or self-directed dying, and indicate how conditions might be changed to increase people's ability to exercise autonomy in self-directing their own death.

Referrals:

***Then*:** In the 1960s, women seeking abortions could turn to organizations such as the Society for Humane Abortion for information about how to obtain foreign, quasi-legal, or illegal abortions, or how to perform do-it-yourself abortions.[340]

***Now*:** People seeking to end their own lives can turn to organizations such as Exit International for information about how to obtain foreign, quasi-legal, or illegal aid, or how to hasten death on their own.[341]

One of the functions of the Society for Humane Abortion was to provide referrals to illegal abortionists. At a time when abortion was generally not available legally, such referrals facilitated the choices of women seeking abortions. As Charlea Massion pointed out in her discussion of the role of the Catholic Church and other religious groups in health care today, even though abortion is legal in many circumstances, obtaining referrals to abortionists may

sometimes be a challenge. So-called “crisis pregnancy centers,” for example, are notorious for not providing abortions and for refusing to provide referrals to facilities that do perform abortions.[342] Catholic health care facilities, too, do not perform abortions (much less assisted dying) and often discourage their staff from referring women to facilities that do provide abortions.[343]

In her formative evaluation of how existing right-to-die laws do and do not support patient autonomy, Oliver notes that end-of-life care providers are generally not required to inform patients about medical aid in dying as a possible option, nor are they required to disclose up front whether their facilities provide physician aid in dying or even make referrals to facilities that do provide this service.[344] This can lead to patients going through the entire request process only to be then denied and left without a referral to a physician willing to give them the specific death they seek.

Whether the issue is abortion or aid in dying, physicians’ failure to disclose their opposition to the desired procedure or to make referrals to physicians who will provide an abortion or aid in dying undermine the autonomy of people seeking these services. Thus, just as women needing abortions relied on organizations such as the Society for Humane Abortion when abortion was illegal, people seeking aid in dying where it is illegal or where it is legal but unavailable to them now sometimes turn to organizations such as Exit International for practical information and referrals. In the context of medical aid in dying being illegal or unavailable, such organizations support the ability of

people to self-direct their own dying. In the jurisdictions where aid in dying is legal, requiring physicians caring for patients at the end of life to discuss all possible options, including assisted dying, requiring them to disclose any personal or institutional conscientious objection to aid in dying, and requiring them to make referrals as appropriate to practitioners who provide aid in dying if they do not, could increase the ability of people at the end of life to self-direct their own death.

Travel:

***Then*:** In the 1960s, women who did not qualify for legal abortions in the continental U.S. could, if they had the means, travel to other places where legal abortions, while not guaranteed, were more available.[345]

Now: People in the U.S. wishing to receive aid in dying can, if they have the means, travel to other countries where legal aid in dying, while not guaranteed, is more available.[346]

In an interview for *Abortion without Apology,* Rowena Gurner quipped that DC9 airplanes flying to Puerto Rico, where abortions were illegal but relatively available, were so frequently filled with women seeking abortions that they were sometimes called "the D&C (Dilation and Curettage) express."[347] She recounted her own experience having to travel to obtain an abortion this way:

> I flew to Puerto Rico. The abortion itself was not bad. The circumstances surrounding it were horrendous. I had developed a terrible case of the flu and was running a high temperature on the plane. I thought to myself, "If this person really is a doctor and sees how terribly ill I am, he won't want to do the abortion!" In addition, I had to be back at my job exactly on time as my boss had

> threatened to fire me if I took any extra time for my "vacation." . . . I was absolutely infuriated by the entire experience.[348] [17]

While women in the U.S. no longer have to travel abroad to seek care, many still have to travel long distances. In South Dakota, where Charon Asetoyer lives, for example, a woman on the Cheyenne River Indian Reservation needs to drive more than 300 miles to access abortion care. Women's access to abortion has been eroded state by state; as of May, 2017, South Dakota and six other states (Kentucky, West Virginia, Missouri, Wyoming, North Dakota, and Mississippi) now have only one abortion clinic within their borders.[349]

As noted above, Brittany Maynard, who moved to Oregon to obtain medical aid in dying, pointed out that this option, which took tremendous personal, financial, and familial resources, is not available to most people. Having to move undermines the self-determination of people seeking aid in dying in states where it is illegal. Legalizing aid in dying in all 50 states, and providing mobile services such as those used in the Netherlands for patients in areas where access to services are limited, would increase the ability of people in all regions of the country to obtain aid in dying if they so desired.

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[17] Off the record, two of the women I interviewed discussed their personal experiences with women's need to cross borders into European countries to seek abortions. The stories they told had different outcomes (one was able to obtain an abortion, one was not), but both agreed that the need to travel long distances to seek aid complicated an already difficult situation.

"How To" Handbooks:

***Then*:** In 1969, women needing abortions could read *The Abortion Handbook for Responsible Women*, which featured the chapters "Faking the Hemorrhage," "How to Reach Your Backyard Abortionist," and "Qualifying for a 'Legal' Abortion."[350]

Now: People seeking to hasten their own death can read books such as *The Peaceful Pill Handbook,* which features the chapters "Carbon Monoxide," "Hypoxic Death and the Exit Bag," and "Introduction to Drugs."[351] They can also read *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying,* which features the chapters "The Cyanide Enigma," "Self-Starvation," "Shopping for the Right Doctor," "Beware the Law," "Who Shall Know," and "After the Self-Deliverance."[352]

When Maginnis and Clarke published *The Abortion Handbook* in 1969, medication abortion was not an option; most abortions were accomplished surgically through dilation and curettage. Since then, physicians in the U.S. have begun prescribing mifepristone (formerly known as RU-486), followed by misoprostol, to accomplish medication abortions in early pregnancy. As Loretta Ross noted, a black market for the "abortion pill" emerged once these drugs came on the market. Mifepristone blocks the body's progesterone, without which pregnancy cannot continue. Misoprostol, which causes the uterus to contract and expel the fetus, when added to mifepristone, increases the success rate of medication abortions to approximately 95 percent.[353] Misoprostol alone also has

a success rate of roughly 80 percent in causing an abortion.[354] This drug was first developed as an ulcer medication and remains available in pharmacies in some countries, over the web, and on the black market. In her article, “The Rise of the DIY Abortion in Texas,” Erica Hellerstein explains that, because misoprostol can be bought in bulk without a prescription in Mexico, it is frequently smuggled across the border and bought on the black market by women in Texas, where reproductive health care options have shrunk as the state has passed more and more restrictions.

Mexico is also one of the countries in which Americans sometimes try to purchase “peaceful pills” to hasten their own death. In *The Peaceful Pill Handbook,* author Philip Nitschke writes that many Americans have obtained Nembutal over the counter at veterinary pharmacies in Mexico, although he notes that as Mexico has tightened its regulations, other countries, such as Thailand, have emerged as alternate sources of drugs.[355] Nitschke is the founder of Exit International, which, like the Society for Humane Abortion before it, disseminates information through written materials and workshops about how to accomplish an illegal procedure.

When a desired procedure or drug is illegal, “how to” manuals, including online resources, can support the self-determination of individuals who are committed to obtaining the procedure or drug nonetheless. Having a trustworthy source of information such as the Society for Humane Abortion or Exit International is imperative. As noted by both Exit International and Women on

Web, a modern group that provides mifepristone and misoprostol to women who cannot obtain abortions in their own countries, ordering drugs (whether to induce abortion or to hasten death) over the internet from unknown sources without guidance regarding the integrity of the supplier or the quality of the drugs can be dangerous. While "how to" manuals support individuals' autonomy, especially in the context of illegality, making the desired drugs legal and more widely available would do much more to support self-determination.

Self Help:

***Then*:** When most abortions were illegal, lay women organized underground groups to provide safe, affordable, affirming abortion experiences.[356]

Now: Lay people organize in ways some say are outside the law to provide reliable, respectful, peaceful death experiences.[357]

As Loretta Ross pointed out, the fact that abortion was widely illegal before the 1973 *Roe v Wade* U.S. Supreme Court decision did not prevent women from obtaining abortions. In the context of illegality, however, most women's options were not optimal. Locating an abortionist was often difficult, many women were vulnerable to extortion and rape, and the experience was frequently frightening and dangerous and sometimes deadly. Jane, Chicago's feminist abortion service, provided safer, more affordable, and more affirming abortion experiences, thus increasing and improving the ability of women needing abortions to exercise agency in their lives.

Today, groups such as the Final Exit Network provide assistance in the form of information and companionship to some people who cannot access aid in dying from physicians. The Final Exit Network surely increases and improves the ability of people seeking to hasten their own death to exercise agency over their dying process. If more liberal aid in dying laws were passed in all 50 states, groups such as the Final Exit Network might not need to exist. Some interviewees, however, saw value in assisted dying services being available in settings not limited to the strictly medical. As mentioned above, Judy Costlow wished there could be a place other than a physician's office where she could receive aid. Laura Mentch, too, envisioned a model different from the medical model in which lay people could provide support and possibly active aid in dying.[18]

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[18] After our interview, Mentch sent me an email explaining that she had just spent a weekend with old college friends; they had discussed their previous efforts to expand childbirth options by promoting women's ability to deliver with the assistance of midwives rather than doctors and to give birth at home if they so chose. Mentch reported that they also discussed the relationship between having the option to give birth at home with the assistance of a midwife and doula and having the option to die at home with similar assistance. She sent me links to articles about "death doulas" and, while none mentioned active aid in dying, most referenced the roles doulas might play to support women and families during the time of childbirth as well as to support individuals and families at the time of

Nationwide laws that allowed aid in dying provided by physicians, and also aid from other para-medical personnel in a variety of settings including in a person's home, could support the ability of individuals to self-direct the place and context of their own death.

Therapeutic Committees:

***Then*:** In the late 1960s, legal abortions were available in a small number of states to women who could receive aid from physicians, usually after convincing a "therapeutic abortion committee" that they met its criteria.[358]

Now: Legal aid in dying is available in a small number of states to people who can receive aid from a physician, usually after convincing two or more doctors that they meet that state's criteria.[359]

By definition, needing approval from a "therapeutic abortion committee" limited women's autonomy in regard to the abortion decision before *Roe v Wade;* women could not choose abortion for reasons of their own, but had instead to convince a panel of others that the abortion was needed for reasons approved of by panel members. As Alice Wolfson said, "Basically, you had to convince them you were going to kill yourself (if you couldn't have an abortion.)" Laura Mentch said, "Today, you have to know the right things to say to all these doctors if you want to get the drugs you need help you die."

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death. The emergence of "death doulas" may bring us closer to the visions alluded to by Mentch and Costlow.

Although the U.S. no longer has “therapeutic abortion committees,” many states now have regulations that require waiting periods, ultrasounds, and other steps before a woman can obtain an abortion. While abortion opponents argue that these and other restrictions, such as requiring abortion clinics to have the infrastructure of a hospital, are designed to safeguard the health of women, abortion rights advocates agree that the true purpose of these hurdles is to make abortion more difficult for women to access, which decreases their ability to self-determine their own lives.

Similar restrictions apply to physician aid in dying in the few states where it is legal. While these restrictions may have been intended as safeguards to prevent abuse, Oliver found that they also present unnecessary barriers to access to care among people who qualify for, and want, aid in dying. Regarding the 15-day waiting period between requests required in Oregon, for example, doctors Oliver interviewed said that 15 days was excessive, and that one week was sufficient for repeated visits and conversations to clarify for them whether the patient’s wish was consistent, well-informed, and without pressure.[360] In fact, several studies across jurisdictions show that 30-40 percent of patients die before their requests can be fully processed, often due to timing requirements.[361] At present, the regulatory balance required to safeguard the autonomy of both those who truly want aid in dying and those who do not may be skewed against those seeking aid, even where aid is legal.

Inclusive Organizing:

***Then**:* In the late 1960s and early 1970s, the mainstream abortion rights movement was led and supported primarily by middle- and upper-class white women.

Now: The mainstream right-to-die movement is led and supported primarily by middle- and upper-class white people.

In the introduction to this dissertation I wrote that my work is guided in part by the conclusion of Jocelyn Downie and Susan Sherwin in their article, "A Feminist Exploration of Issues around Assisted Death," that " . . . a feminist analysis supports a permissive policy with respect to assisted death, provided that care is taken in establishing the policy to avoid increasing (or failing to decrease) the oppression of women and other oppressed groups."[362] As explained above, I have learned through my research that assisted dying may be a higher priority for more privileged women (consequently usually white) than for less privileged women. It may seem logical, therefore, that the majority of women actively supporting self-directed dying are white. Yet when I asked interviewees, "Who needs to be at the table to ensure that the right-to-die agenda going forward increases the well-being of all people (or at a minimum does not decrease the well-being of any people)?," respondents—especially women of color—believed that, ideally, the right-to-die movement should include and reflect the experiences of a diversity of people including poor people, people living with disabilities of various kinds, and people of color. Based on interviewee's input,

suggestions about how this might be accomplished are included near the end of this chapter.[19]

In spite of the fact that they acknowledged similarities between the movements for abortion and self-directed dying, most women also saw the issues as very different. In reviewing the literature and the interview transcripts for clues about why interviewees saw the issues as so different and why most were so much more willing to limit access to a hastened death than to limit access to abortion, I identified four possible reasons.

First, many people who support abortion see a distinction between a fully formed human being and a developing mass of pregnancy tissue. Laura Kaplan, whom I did not interview formally about the right-to-die movement but with whom I discussed my work, said that she did not consider making a decision to end

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[19] In her interview, Ku'umeaaloha Gomes, who had been raised as a Catholic, described being in the hospital following her abortion; the abortion decision had been difficult for her and she felt very alone. A hospital priest came to her room and said he would like to pray with her, and she felt comforted. When he asked her why she was there and she told him, however, he said she had sinned, declined to pray with her, and left her alone. In answer to the question about who should be at the policy-making table, this experience led her to point out that perhaps there are some who should not have a place at the table because of their judgmental attitudes about such deeply personal decisions.

one's own life as equivalent to making a decision to end the life of a fetus because she did not consider the fetus to be a person.[20]

Second, whereas a woman who decides to have an abortion today can still decide to have a child in the future, a person who commits suicide today cannot decide to come back to life in the future. Charlea Massion said that she regarded a decision to commit suicide as "more momentous by many orders of magnitude" because of its finality.

Third, I suspect that most abortion activists are less likely to disagree with or possibly see as a tragedy a person's decision to have an abortion than to disagree with or possibly see as a tragedy a person's decision to commit suicide. Even if a woman is ambivalent about having an abortion, one might conclude that her ambivalence about having a child, which is itself a momentous decision, likely indicates that terminating the pregnancy may very well be an appropriate choice at the time. And, fewer people are likely to know about a woman's decision to have an abortion than to know about the deliberate death of a family member or friend. When a person—especially someone who is not terminally ill—hastens his or her own death, those left behind may not understand the

[20] Somewhat conversely, Judy Costlow reported that a friend with whom she had discussed this project saw the issues as different because in deciding to end your own life, you were making a decision about your life only, whereas in deciding to have an abortion you were ending the life of another.

decision, disagree with it, or experience feelings of guilt or grief to a much greater extent than would likely be the case after most abortions.

Finally, while a decision to terminate a pregnancy or to hasten one's own death may both result in practical outcomes, having the ability to control the circumstances of one's death may draw more deeply on a person's existential need to maintain autonomy. Liz Szabo of the *Washington Post* reports:

> "The dominant reasons for wanting euthanasia or assisted suicide are psychological and involve control factors," said Ezekiel Emanuel, chair of medical ethics and health policy at the University of Pennsylvania's medical school. He noted that most of those who have used aid-in-dying laws are white, well insured and college-educated. "These are people who are used to controlling every aspect of their lives, and they want to control this aspect of their lives."[363]

As Loretta Ross pointed out, individuals' understanding of autonomy may be culturally influenced. She posited that, in Western cultures, autonomous decision-making has traditionally been viewed as a process in which the decision-maker is more isolated and alienated, less enmeshed in community, than is the case in, for example, African and African-American communities influenced by the more communal philosophy of Ubuntu. The historic linking of autonomy and alienation from relationships with others in Western philosophies of autonomy is precisely what feminists have critiqued in their development of the concept of relational autonomy.

In fact, Pam Oliver's research for *Addressing Access Barriers to Legal Assisted Dying* indicates that end-of-life decision-making is typically highly relational.[364] People considering hastening their own death in jurisdictions where

aid in dying is legal commonly call on family members to help them find information and to think through their options and the reasons for their choices.[365] Their decision-making process is relational not only at the micro level in terms of their interactions with family and close others but also at the macro level in terms of laws and policies regarding the availability of medical, social, and financial supports.[366]

Oliver's observation that end-of-life decision-making is generally relational on many levels is entirely consistent with Ross's contention that decision-making may be influenced by cultural considerations. As Ross pointed out, decision-making from one culture to another may differ not so much in terms of *who* make the final decision but in terms of what considerations are included in the decision-making process, of *why* a particular decision is made. And, as Battin states, if society were to embrace the concept of self-directed dying, people would likely self-direct their own dying in many different ways.[367] For example, some might choose medical aid in dying, some might choose to leave the matter in the Creator's hands, some might choose another option, all depending upon their own particular options, values, and beliefs.

Conclusions

Highlighting parallels between abortion and self-directed dying may not be an effective way to increase veteran reproductive freedom activists' support for the right-to-die, but lessons learned in the reproductive freedom movement about

the limitations of single-issue agendas and the importance of inclusive organizing could be applied to the right-to-die movement.

The ability to actively hasten one's own death, and to have assistance in doing so, may well be a higher priority for more, rather than less, privileged women. While none of the women I spoke with opposed assisted dying, some saw it as a relatively low priority, while others saw it as a more important issue. Among those who saw it as relatively important, most indicated that they believed the option of assistance in hastening one's own death should not be limited to individuals with a six-month terminal diagnosis. They supported extending this option to people experiencing other physical and psychological conditions that made their quality of life unacceptable to them. Almost all of these women, though, rejected the idea of making "peaceful pills" widely available without regulation. They wanted some form of protection against coercion, murder, or impulsive suicide. (For U.S. suicide statistics see Appendix B.) Most implicitly or explicitly agreed that someone—perhaps not only doctors, but at least someone with the training or capacity to conduct some sort of evaluation—should serve as the gateway to "peaceful pills." In short, most interviewees who saw aid in dying as something of a priority issue did not necessarily want the repeal of all assisted dying laws, nor did they want complete deregulation of "peaceful pills." On the other hand, they did want "peaceful pills" to be more available to more people. Most did not necessarily believe that doctors should be the only gateway to "peaceful pills," nor did they believe that a mental illness should automatically

disqualify someone from receiving aid, or that a person should have to have a terminal diagnosis to obtain assistance. Luz Rodrigues seemed to voice the sentiments of many women when she said, “I pretty much feel that you can never have too much freedom as a human being.” They would likely support much less restrictive right-to-die laws than are currently being passed in the U.S.

Among other women, the ability to receive assistance in actively hastening one’s own death was seen as less of a priority than other end-of-life issues. These included not only legal patient’s rights such as the ability to refuse unwanted medical treatments or to create advanced medical directives but also the ability to care for, and be cared for, in more supportive settings. Interviewees prioritized policy and environmental changes to better support caregivers. Suggestions included better housing options (decent housing in which the frail or dying person could be cared for by family at home and/or acceptable facilities very close to the family home); more caregiver-friendly work policies; and increased availability of elder-care and adult day care services, including appropriate in-home health care, housekeeping, and companion options.

To my knowledge, while some segments of the right-to-die movement have expanded their agendas beyond active aid in dying to promote the use of advanced directives and to encourage doctors to have more frank discussions with patients about their wishes regarding treatment, the movement is not prioritizing allegiances with broad efforts to support caregivers or people at the end of their lives who are in need of assistance for continuing to live. Movement

leaders also seem understandably cautious about publicly suggesting that anyone other than doctors should be able to serve as the gateway to “peaceful pills” or that anyone other than terminally ill individuals should be able to obtain “peaceful pills” or assistance in using other methods to produce peaceful, reliable death.

My primary conclusion is that by actively embracing efforts to support caregivers and to promote quality care for all at the end of life, right-to-die organizations might build trusting coalition or network relationships with communities that do not prioritize, and that have experienced histories that might understandably lead them to view skeptically, physician-assisted dying and other forms of assisted suicide. Strategically, this might help neutralize potential opposition to legal aid in dying. More importantly, it might help members of these communities increase their ability to self-direct their own dying, not necessarily by increasing their access to “peaceful pills” but rather by increasing their ability in end-of-life situations to care for and be cared for as they see fit.

My further conclusion is that if right-to-die organizations were to expand their model policies beyond those that depend on physician involvement, demand a six-month terminal diagnosis, potentially disqualify individuals experiencing mental anguish, and in some circumstances place overly burdensome requirements on patients regarding travel to doctors’ offices, waiting periods, etc., they would find that veteran reproductive freedom activists’

commitment to self-determination would lead some of these women to approve of, and perhaps actively support, less restrictive right-to-die policies.

Taken together, these two developments—promoting less restrictive policies regarding access to active assistance in dying, and promoting more supportive policies regarding family caregiving and other forms of medical and social care for the ill, disabled, frail elderly, and people at the end of life—might more broadly and deeply engage U.S. women in their 60s, 70s, and 80s in an end-of-life movement. (For a possible model for integrating end-of-life issues into women's health activities, see Appendix C.) And, again taken together, these two developments could increase women's autonomy through the life span, potentially as caregivers and potentially as women at the end of life, in ways that would allow them to determine their own various experiences with the end of life they saw fit.

Whether or not women's health organizations will eventually include end-of-life concerns as priority issues in their action agendas remains to be seen. The fact that interviewees did not generally consider dying to be a women's issue suggests that this is unlikely. On the other hand, feminist health organizations have sometimes prioritized issues that are not specific to women. For example, in 2003, long before President Obama was elected or the Affordable Care Act (popularly known as Obama-care) was proposed, the National Women's Health Network prioritized affordable, accessible, quality healthcare for all as one of its top three goals. "Healthcare for all" applies not just to women but to everyone. In

2007, the National Women's Health Network partnered with the Black Women's Health Imperative and the MergerWatch Project to create "Raising Women's Voices for the healthcare we need" (RWV). RWV was, and continues to be, based on the idea that "women are grassroots experts in what is wrong with the current health system and what it takes to fix it because of our roles as arrangers of health care for our families." Just as "healthcare for all" was not an explicit focus of feminist women's health organizing in the 1970s but became one in the first decade of the 21st century, so, too, might end-of-life concerns be included in the agendas of feminist health organizers in the years to come. While interviewees may not have seen dying as a women's issue, they did not dispute that disparities in finances and life expectancies between men and women may often make dying a gendered experience. They also understood that throughout much of American society the work of end-of-life caretaking is disproportionately performed by women. Even if their own potentially gendered experience of dying does not motivate women to embrace end-of-life issues as issues deserving of attention by feminist health activists, their role as caretakers might, to quote RWV, make them "grassroots experts" on what is needed in an end-of-life movement.

Whether an effort in the United States to promote less restrictive policies regarding access to active assistance in dying and, simultaneously, more supportive policies regarding family caregiving and other forms of medical and social care for the ill, disabled, frail elderly, and people at the end of life were to

come about through women's health organizations or another source, it would likely develop in a way particular to America. The reproductive justice movement was created in America to advance and protect reproductive freedom for diverse women by incorporating a core commitment to addressing medical, social, economic, and racial and ethnic injustices that limit many American women's reproductive choices. The creators of the reproductive justice movement were aware of various forms of oppression of women around the world and of many local and global efforts to improve quality of life and increase self-determination among women facing both shared and situation-specific challenges. The American reproductive justice movement was shaped not only by its founders' awareness of women's struggles globally but also by their understanding of the struggles of diverse women in America. As their writings and interviews make clear, slavery and its legacy, the colonization and even genocide of indigenous people, and the widespread and longstanding adoption of eugenic programs and practices are American injustices that the reproductive justice movement has, and is, addressing. By developing a movement that insists that women should have access to abortion but also that the context in which women make the abortion decision should include better options, the reproductive justice movement promotes women's ability to self-determine their own lives. The American right-to-die movement could do the same. It could take into account in its organizing efforts America's historical population control efforts including slavery, colonization, and eugenics, as the reproductive justice movement has

done. Similarly, it could be shaped by other uniquely American challenges, including: America's status among the countries where aid in dying is legal in any jurisdiction as the only nation without universal health care; the nation with the highest poverty rate; and the nation with the weakest social safety net. An inclusive American end-of-life movement seeking to advance and protect choice at the end of life for diverse people would, of necessity, be uniquely American.

Reflection

The insights I acquired in the interviews I conducted required me to broaden my original agenda, which began as a search for tactical assistance for the right-to-die movement. (I wrote the initial draft of a possible blueprint for increasing women's support for self-directed dying, presented in Appendix C, before the first interview; as a result of lessons I learned through the interviews, I significantly revised it to include and ultimately make more central end-of-life concerns other than medical aid in dying.) End-of-life issues are complicated, especially when viewed across cultures, and the parallels between ending the growth of a fetus developing in a woman's uterus through abortion and ending the life of a fully-formed person are far from exact. Nonetheless, both issues touch on the quality of a life to be lived. Abortion concerns the quality of life for the woman, her significant others, and a potential child. Self-directed dying—choosing, as much as possible, the time, place, means and circumstances of one's own death—concerns the quality of life for the dying person and, likely, his

or her significant others. In both cases, the meaning of the choice is contingent on the context in which the individual is making her or his decision.

[337] Kimi Morton Chun, "Peggy Chun: "Peg's Legs"," https://sharethecare.org/pegs-legs/.

[338] Stephen Feller, "Drug Company Hikes Price of End-of-Life Drug Seconal," UPI, http://www.upi.com/Health_News/2016/03/28/Drug-company-hikes-price-for-end-of-life-drug-Seconal/2791459184866/.

[339] Chalker is not the only one to have concerns about freedom of information regarding self-directed dying. While she concludes that free speech and open access to information is important, however, the Minnesota Supreme Court disagrees. Below is an excerpt from the Final Exit Network Newsletter published in March of 2017:

> **FEN takes Death with Dignity case to the U.S. Supreme Court**
>
> The Board of Directors of Final Exit Network has authorized an appeal to the Supreme Court of the United States from the corporation's conviction in Minnesota on a charge of "assisting" in a "suicide."
>
> On Tuesday, March 14, the Supreme Court of Minnesota declined to review the Network's 2015 conviction. The Network's petition for review by the Supreme Court of the United States is required to be filed within 90 days of the Supreme Court of Minnesota's denial of review.
>
> In May 2015, Final Exit Network, Inc. was convicted by a jury in Hastings, Minnesota of "assisting" in a "suicide" for having provided Exit Guide services to a woman who elected to terminate her extreme suffering. The Network was fined $30,000 and required to pay an additional $3,000 in restitution to the "victims," the family of the deceased Network member, to cover her funeral expenses.
>
> The Network appealed the 2015 conviction to the intermediate Court of Appeals of Minnesota, which affirmed the conviction last December. The Supreme Court of Minnesota denied review of the Court of Appeals' decision.
>
> Even though it was established at the trial that the Network's Exit Guides, in accordance with the Network's practices and protocols, did not provide any physical assistance in the death, the Network was convicted merely for giving information to Doreen Dunn, 57, of Apple

> Valley, Minnesota.
>
> Under the Minnesota courts' interpretation of that state's law against "assisting" in a "suicide," the Network was convicted for giving the Apple Valley member the website address where she could purchase Derek Humphrey's landmark bestseller, "Final Exit," the Network's namesake.
>
> In all the Minnesota courts, the Network has asserted and will continue to assert in the Supreme Court of the United States that Final Exit Network's giving of information to its members is a First Amendment-protected exercise of free speech, and therefore Minnesota cannot make it a crime.
>
> "No other state in the country makes it a crime to give information about self-deliverance," said the Network's president, Janis Landis.

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APPENDICES

APPENDIX A

PRE-INTERVIEW INFORMATION AND QUESTIONS PROVIDED TO WOMEN INTERVIEWED

Our Bodies, Our Lives, Our Right to Decide?

Please share your thoughts & experiences in a 90-minute confidential interview. (Details on next page.)

Abortion, Reproductive Justice, and Self-Directed Dying

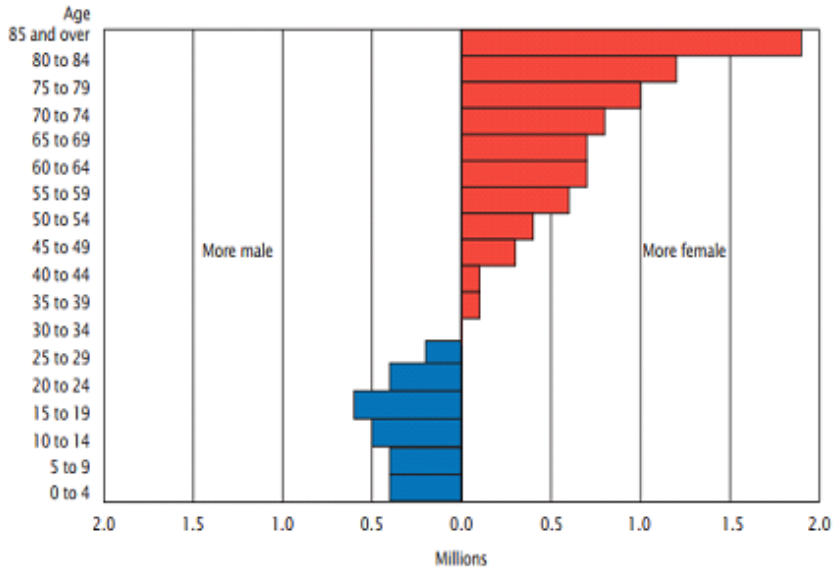
In the 1960s and early 1970s a major concern for women's health and self-determination was access to safe abortions.

Today a growing concern for women's and men's health and self-determination is access to peaceful death.

- Could highlighting parallels between the early abortion rights movement and the current right-to-die movement motivate mature women to support self-directed dying?
- What lessons might veterans of the abortion and reproductive justice movements offer to current right-to-die activists?

In 2010, women 85 and older outnumbered men 85 and older. Projections through 2050 indicate that the gender gap in life expectancy will continue at least through the next four decades. There are, and will continue for the foreseeable future to be, more old women than old men.

Figure 1: Differences between Male and Female Populations by Age, 2010



Source: U.S. Census Bureau

Most of the women who led the fight for abortion rights in the 1960s and 1970s were born between 1930 and 1955. These veteran activists are now in their 60s, 70s, and 80s. (See outlined age/sex cohorts in Figures 2 and 3, on the next page.) During their potential childbearing years, these women fought for more control over whether, when, and how they reproduced. As they progress through the life span, might some now fight for more control over how and when they die?

INTERVIEW DETAILS:

My name is Ninia Baehr. I am doing research for an American Studies dissertation that draws on women's history. My goal is to determine whether, and how, veterans of the abortion and reproductive justice movements might be motivated to shape the evolving right-to-die movement.

I hope to interview approximately a dozen women for about 90 minutes each. To be eligible for this study, women will have been of childbearing age before the 1973 US Supreme Court *Roe v. Wade* abortion decision and will support women's right to abortion.

I will strive to ensure that at least 50% of the women interviewed identify themselves as women of color and that at least 20% of the women interviewed identify themselves as women living with long-term disabilities and/or as women caring for children or other friends and family living with long-term disabilities.

Interviews will be conducted over the phone and will be recorded. Recordings and/or transcripts of interviews will not be made public without the interviewee's consent, but quotations not linked to names or other identifying information may be included in my dissertation or subsequent publications.

In the interviews I will invite women to respond to questions of their choice. The list of questions from which interviewees can choose is on the back of this pamphlet.

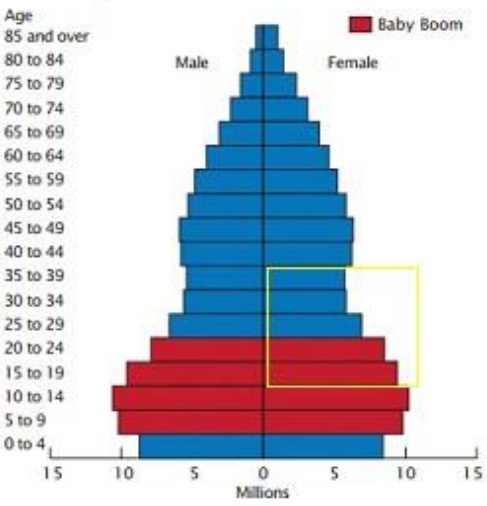
This research will draw on an oral history format. I will ask each woman interviewed to talk about experiences in her own life that she believes inform her answers to the questions she chooses to address.

Women will not be paid for their participation, but the first 12 women who are selected to participate and who complete an interview will be able to specify one non-profit to which $100 will be contributed.

Women interested in being interviewed can call me at 406-579-8884 or e-mail me at niniab@outlook.com.

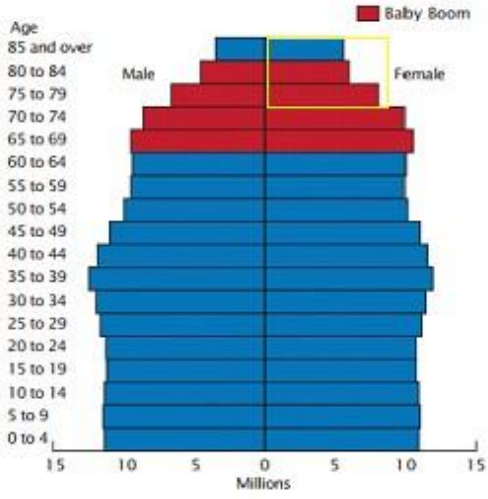
Cohort of women who led the abortion movement in the 1960s and 1970s (highlighted).

Figure 2: Population by Age and Sex, 1970



Source: US Census Bureau

Figure 3: Population by Age and Sex, 2030



Source: US Census Bureau

THEN and NOW

Abortion (1960s – 1970s) **Assisted Dying (Today)**

- *Then:* In the U.S. in the 1960s, assisting a woman in aborting an unwanted pregnancy was illegal in almost all circumstances.

  Now: In the U.S. today, assisting someone in hastening his or her own death is illegal in almost all circumstances.
- *Then:* In the 1960s, women who did not qualify for legal abortions in the U.S. could, if they had the means, travel to countries where legal abortions, while not guaranteed, were more available.

  Now: People in the U.S. wishing to receive aid in dying can, if they have the means, travel to other countries where legal aid in dying, while not guaranteed, is more available.
- *Then:* When most abortions were illegal, some physicians provided them anyway.

  Now: Aid in dying is usually illegal, but some physicians provide it anyway.
- *Then:* When most abortions were illegal, women sometimes tried to fake a miscarriage to trick a doctor into providing a D&C procedure to clean out the uterus (or end a pregnancy).

  Now: When aid in dying is usually illegal, some people fake pain or insomnia to try to trick doctors into giving them drugs to bring about peaceful death.
- *Then:* When most abortions were illegal, lay women organized underground groups to provide safe, affordable, affirming abortion experiences.

  Now: Lay people organize in ways some say are outside the law to provide reliable, respectful, peaceful death experiences.
- *Then:* In the late 1960s, legal abortions were available in a small number of states to women who could receive aid from physicians, usually after convincing a "therapeutic abortion committee" that they met its criteria.

  Now: Legal aid in dying is available in a small number of states to people who can receive aid from a physician, usually after convincing two or more doctors that they meet that state's criteria.
- *Then:* In the past half century, abortion has sometimes been treated as a "single issue" rather than as part of a broader women's health or reproductive justice agenda.

  Now: Legalizing assisted suicide is sometimes treated as a "single issue" rather than as a part of a broader patients' rights or medical justice agenda.
- *Then:* In the late 1960s and early 1970s and beyond, the mainstream abortion rights movement was led and supported primarily by middle- and upper-class white women.

  Now: The mainstream right-to-die movement is led and supported primarily by middle- and upper-class white people.

QUESTIONS

In what ways, if any, do you consider dying to be a "women's issue," and in what ways, if any, do you not consider it not to be a "women's issue?"

In what ways is the issue of controlling whether, when, and how you reproduce similar to the issue of controlling when and how you die, and in what ways is it different?

What conditions are necessary for the concept of "choice" to be truly meaningful in self-directed dying?

What do you think about the fact that people who want assistance in hastening death sometimes travel or move to get the services they seek?

What do you think about the fact that people who want assistance in hastening their own death sometimes resort to subterfuge?

What should be the requirements for receiving aid in dying?

Who should, and who should not, be prevented from hastening his or her own death?

Who should be able to assist those who want to hasten death?

What might be the dangers, and what might be the advantages, of involving doctors in providing (or denying) aid in dying?

What good things, and what bad things, might happen if "peaceful pills" (drugs to bring about a peaceful death) were available without prescriptions?

What laws, if any, should regulate assisted suicide?

What do you think about the idea that death might sometimes be seen not as something that *happens to you* but as something *you do*, a final, culminating activity?

What do you think about the idea of reconceiving suicide as a civil right?

In what ways, and to what extent, are issues related to self-directed dying priorities for the people you know?

Who needs to be at the table to ensure that the right-to-die agenda going forward increases the well-being of all people (or at a minimum does not decrease the well-being of any people)?

What other questions need to be asked?

APPENDIX B:

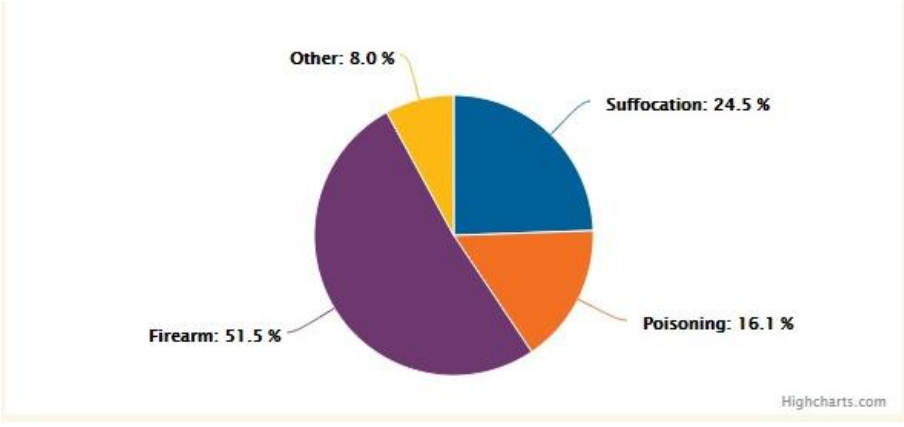
SUICIDE STATISTICS IN THE U.S.

Suicide Statistics in the U.S.

The National Institute of Mental Health (NIMH) reports that suicide was the tenth leading cause of death in the U.S. in 2010, the latest year for which it has reliable statistics. According to the World Health Organization (WHO), the U.S. suicide rate was 7.6 suicides per 100,000 people in 1950. The rate increased gradually through 1975, when it reached 12.7; since then, it has ranged as low as 10.4. According to the American Foundation for Suicide Prevention (AFSP), the total rate for 2013 was 12.6.

The majority of completed (as opposed to attempted) suicides are accomplished by use of firearms. As Figure 1 illustrates, in 2013, after firearms, suffocation was the second leading mechanism, followed by poisoning, with only 8 percent of suicides being completed through other methods.

Figure 1: Suicide Death by Method, 2013.



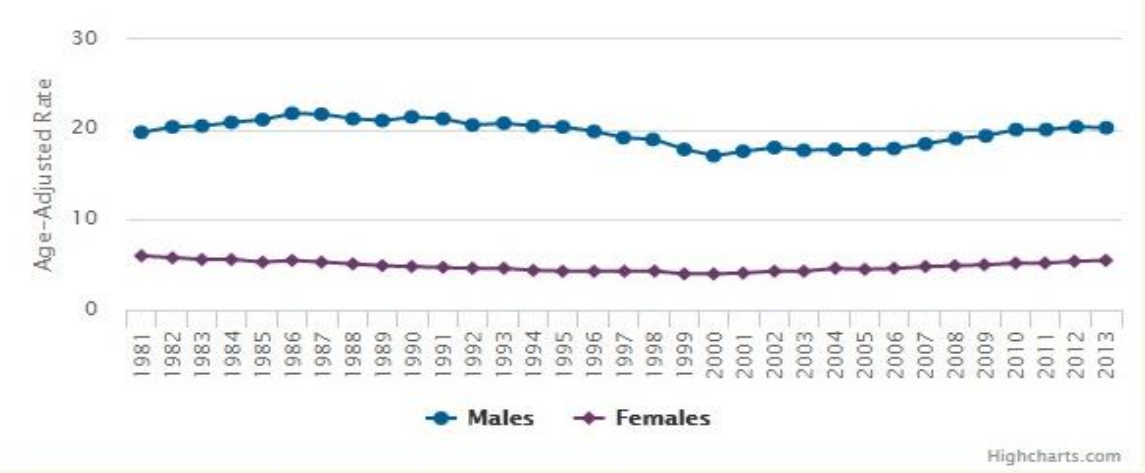
Source: American Foundation for Suicide Prevention. Available at https://afsp.org/about-suicide/suicide-statistics/

The causes of suicide are difficult to determine, but data published by the CDC suggest that both alcohol and a current mental health issue (especially depression) are frequently associated with suicide.

Suicide Rates and Gender

As Figure 2 shows, males are approximately four times more likely than females to die by suicide.

Figure 2: Suicide Rates by Sex from 1981 to 2013.



Source: American Foundation for Suicide Prevention. Formerly available at http://www.afsp.org/understanding-suicide/facts-and-figures, accessed 4/22/15. For additional information on suicide rates by sex see Suicide Rates for Females and Males by Race and Ethnicity: United States, 1999 and 2014 available at https://www.cdc.gov/nchs/data/hestat/suicide/rates_1999_2014.htm

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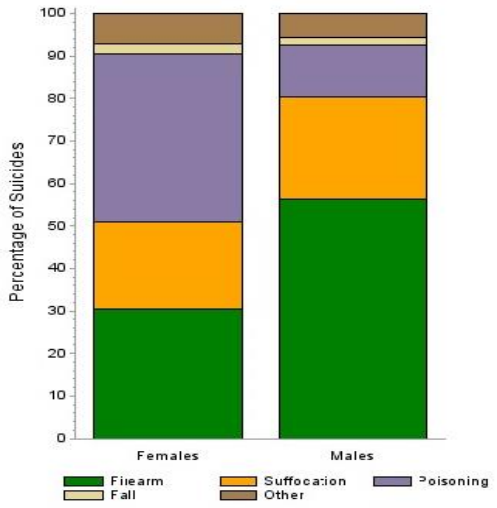
Although females report higher levels of depression and suicidal ideation and attempt suicide more frequently, males are more likely to complete suicide.

One possible explanation for this difference is that, as Figure 3 shows, males are more likely to use immediately lethal methods, such as firearms or asphyxiation.

Figure 3: Percentage of Suicides Among Persons Ages 10 Years and Older, by Sex and Mechanism, 2005-2009.



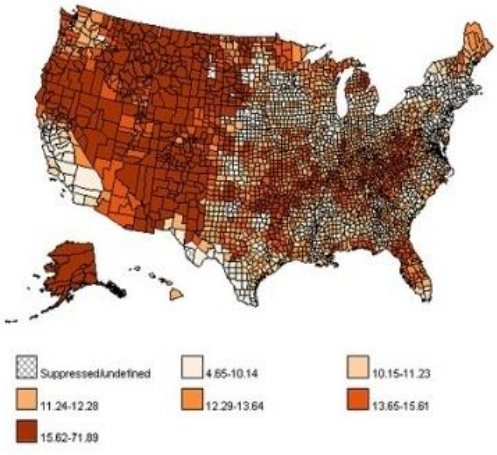
Source: CDC. National Center for Injury Prevention and Control, Division of Violence Prevention. Formerly available (as of 4/22/15) at http://www.cdc.gov/violenceprevention/suicide/statistics/mechanism01.html.

Suicide Rates and Region

As Figure 4 illustrates, in 2000-2006, suicide rates were disproportionately high in western states, in certain sections of Appalachia, in southern Oklahoma, and in northern Florida. According to AFSP, at 23.7 suicides per 100,000 people, the suicide rate in Montana was higher than in any other state. As Figure 5 shows, suicide rates are highest in rural areas. The phenomenon of

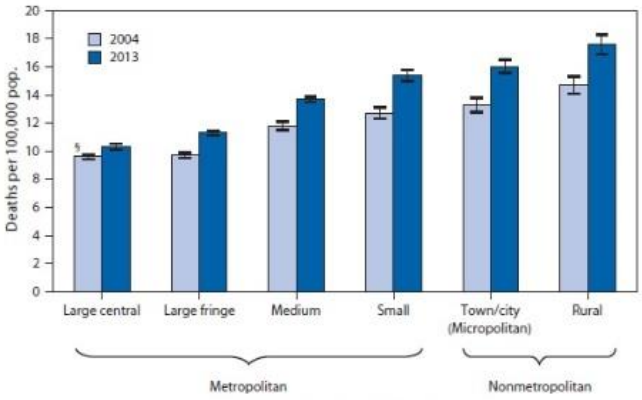
disproportionately high suicide rates in rural areas among adolescents and young adults, in particular, has received scholarly attention. Publishing in March, 2015, in JAMA Pediatrics, for example Cynthis Fontanella suggests that cultural variables, such as a strong rural belief in self-sufficiency, combined with lack of access to mental health services, may place rural youth at particular risk.

Figure 4: Smoothed, Age-adjusted Suicide Rates per 100,000 population, by County, 2000-2006



Source: CDC. National Center for Injury Prevention and Control, Division of Violence Prevention. Available at http://www.cdc.gov/violenceprevention/suicide/statistics/suicide_map.html.

Figure 5: Rate for Suicide by Urbanization of County of Residence, 2004 and 2013

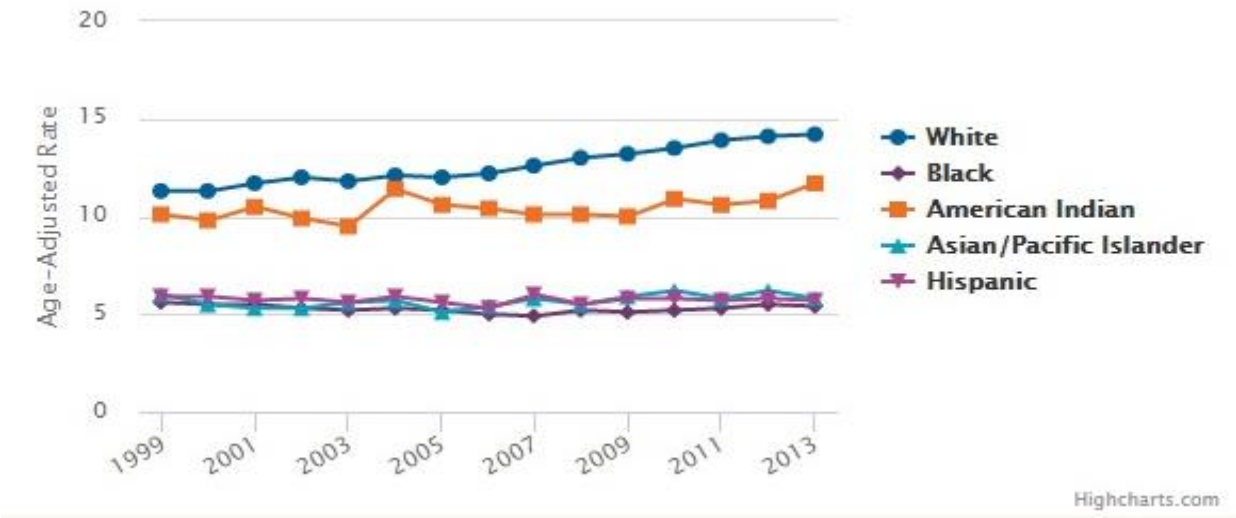


Source: CDC. Available at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6414a9.htm?s_cid=mm6414a9_wS

Suicide Rates and Race/Ethnicity

As Figure 6 shows, in 1999-2013, Non-Hispanic Whites had the highest suicide rates, followed by American Indians. Blacks, Hispanics, and Asian/Pacific Islanders had significantly lower rates. Important differences between ethnic groups are evident across the lifespan.

Figure 6: Suicide Rates by Ethnicity from 1999 to 2013.



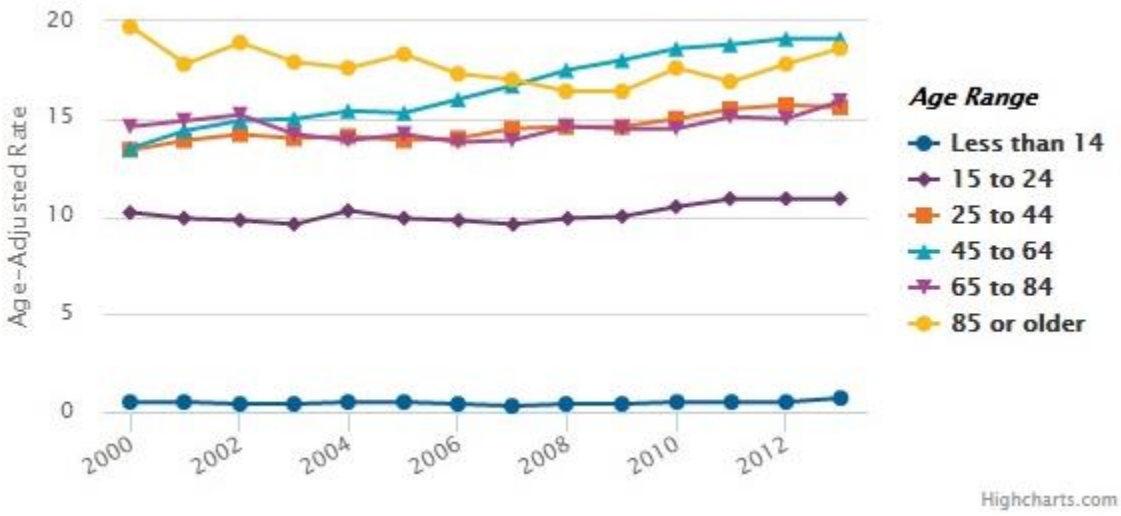
Source: American Foundation for Suicide Prevention. Available at http://www.afsp.org/understanding-suicide/facts-and-figures.

Suicide Rates and Age

Suicide in the Young

Historically, suicide prevention efforts have focused on the young and the elderly. In the case of the young, this is not because of higher suicide rates. In fact, with very important exceptions such as American Indian young people and, perhaps, Gay, Lesbian, Bisexual, or Transgender (LGBT) young people, suicide rates among people age 24 and younger are significantly lower than rates among older age groups, as Figure 7 illustrates.

Figure 7: Suicide Rates by Age from 2000 to 2013.



Source: American Foundation for Suicide Prevention. Available at http://www.afsp.org/understanding-suicide/facts-and-figures.

One possible explanation for the focus on youth suicide prevention could be that the suicide of young people may be viewed as especially tragic. Young people may be regarded as particularly susceptible to impulsivity, since their incomplete development of the frontal lobe of the brain, combined with their relatively short life experience, may combine to limit their ability to fully register the consequences of their actions. Their suicides doubtless cause their families enormous grief, and, compared to people who commit suicide at an older age, they lose more years of potential life. A second possible explanation may be that, in spite of the relatively low suicide rates among young people, suicide is the 3rd leading cause of death among people age 10-14 and the second leading cause

of death among people age 15-34. As Figure 8 demonstrates, young people in 2013, for example, were relatively unlikely to die of stroke, heart disease, diabetes, kidney diseases, or other common illnesses, making suicide (along with unintentional injury) notable in an otherwise healthy population.

Figure 8: 10 Leading Causes of Death by Age Group, 2013.

	Age Groups										
Rank	<1	1-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65+	Total
1	Congenital Anomalies 4,758	Unintentional Injury 1,316	Unintentional Injury 746	Unintentional Injury 775	Unintentional Injury 11,619	Unintentional Injury 16,209	Unintentional Injury 15,354	Malignant Neoplasms 46, 185	Malignant Neoplasms 113,324	Heart Disease 488,156	Heart Disease 611,105
2	Short Gestation 4,202	Congenital Anomalies 476	Malignant Neoplasms 447	Malignant Neoplasms 448	Suicide 4,878	Suicide 6,348	Malignant Neoplasms 11,349	Heart Disease 35,167	Heart Disease 72,568	Malignant Neoplasms 407,558	Malignant Neoplasms 584,881
3	Maternal Pregnancy Comp. 1,595	Homicide 337	Congenital Anomalies 179	Suicide 386	Homicide 4,329	Homicide 4,236	Heart Disease 10,341	Unintentional Injury 20,357	Unintentional Injury 17,057	Chronic Low. Respiratory Disease 127,194	Chronic Low. Respiratory Disease 149,205
4	SIDS 1,563	Malignant Neoplasms 328	Homicide 125	Congenital Anomalies 161	Malignant Neoplasms 1,496	Malignant Neoplasms 3,673	Suicide 6,551	Liver Disease 8,785	Chronic Low. Respiratory Disease 15,942	Cerebro-vascular 109,602	Unintentional Injury 130,557
5	Unintentional Injury 1,156	Heart Disease 169	Chronic Low. Respiratory Disease 75	Homicide 152	Heart Disease 941	Heart Disease 3,258	Homicide 2,581	Suicide 8,621	Diabetes Mellitus 13,061	Alzheimer's Disease 83,786	Cerebro-vascular 128,978
6	Placenta Cord. Membranes 953	Influenza & Pneumonia 102	Heart Disease 73	Heart Disease 100	Congenital Anomalies 362	Diabetes Mellitus 684	Liver Disease 2,491	Diabetes Mellitus 5,899	Liver Disease 11,951	Diabetes Mellitus 53,751	Alzheimer's Disease 84,767
7	Bacterial Sepsis 578	Chronic Low. Respiratory Disease 64	Influenza & Pneumonia 67	Chronic Low Respiratory Disease 80	Influenza & Pneumonia 197	Liver Disease 676	Diabetes Mellitus 1,952	Cerebro-vascular 5,425	Cerebro-vascular 11,364	Influenza & Pneumonia 48,031	Diabetes Mellitus 75,578
8	Respiratory Distress 522	Septicemia 53	Cerebro-vascular 41	Influenza & Pneumonia 61	Diabetes Mellitus 193	HIV 631	Cerebro-vascular 1,687	Chronic Low. Respiratory Disease 4,619	Suicide 7,135	Unintentional Injury 45,942	Influenza & Pneumonia 56,979
9	Circulatory System Disease 458	Benign Neoplasms 47	Septicemia 35	Cerebro-Vascular 48	Complicated Pregnancy 178	Cerebro-vascular 508	HIV 1,246	Septicemia 2,445	Septicemia 5,345	Nephritis 39,080	Nephritis 47,112
10	Neonatal Hemorrhage 389	Perinatal Period 45	Benign Neoplasms 34	Benign Neoplasms 31	Chronic Low. Respiratory Disease 155	Influenza & Pneumonia 449	Influenza & Pneumonia 881	HIV 2,378	Nephritis 4,947	Septicemia 28,815	Suicide 41,149

Source: CDC. National Center for Injury Prevention and Control. Available at http://www.cdc.gov/injury/images/lc-charts/leading_causes_of_death_by_age_group_2013-a.gif

Suicide in the Elderly

Unlike the focus on youth suicide prevention, the historic focus on elderly suicide prevention could be said to be based on disparate rates of suicide according to age. In 1950, suicide rates among people age 65 and older were 30 per 100,000, significantly higher than any other age group then or now. Over the decades, the suicide rate among the elderly decreased. In this century, the suicide rate among people age 85 and older has ranged between 17 and 20; as Figure 7 shows, this age group had the highest suicide rate of any age group until 2008, when rates for people age 45-64 surpassed rates for people 85 and older. Although the rate of suicide among the elderly is high compared to that of other age groups, as Figure 8 shows, it was not among the top ten causes of death for that age group in 2010.

Suicide in the Middle-Aged

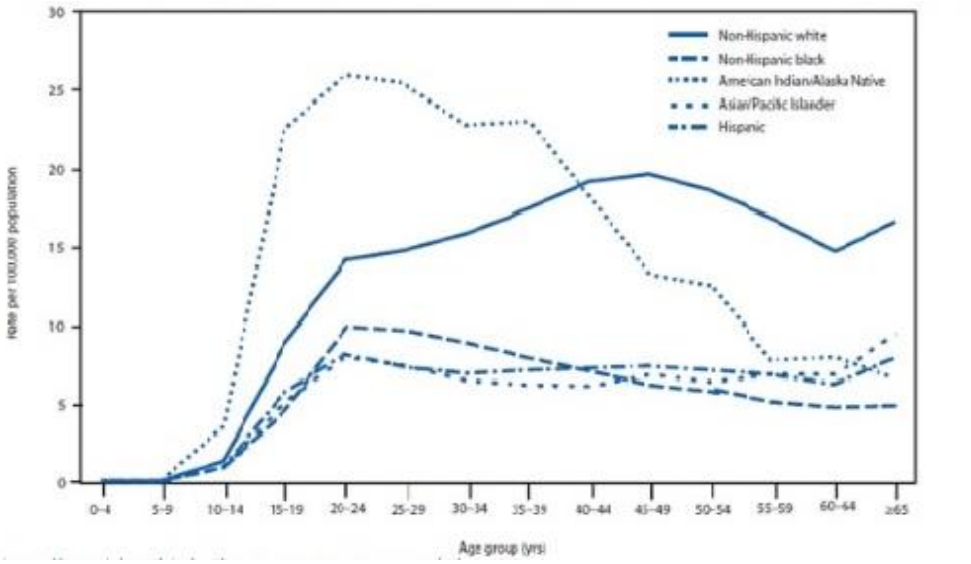
As a cohort, Baby Boomers (those born between 1946 and 1964), have had higher suicide rates than have earlier generations. Today the age range of Baby Boomers is 53 – 71. As Figure 7 demonstrates, suicide rates among people age 45-64 are now the highest in the nation. Rates among people in their 50s have increased most, especially among Non-Hispanic White and American Indian/Alaska Native males.

Vulnerable Groups

American Indian/Alaska Native Youth and Young Adults

As Figure 9 demonstrates, in 1999-2007, American Indians/Alaska Natives in their teens, 20s, and 30s had the highest rates of suicide.

Figure 9: Suicide Rates by Race/Ethnicity and Age Group, 1999-2007

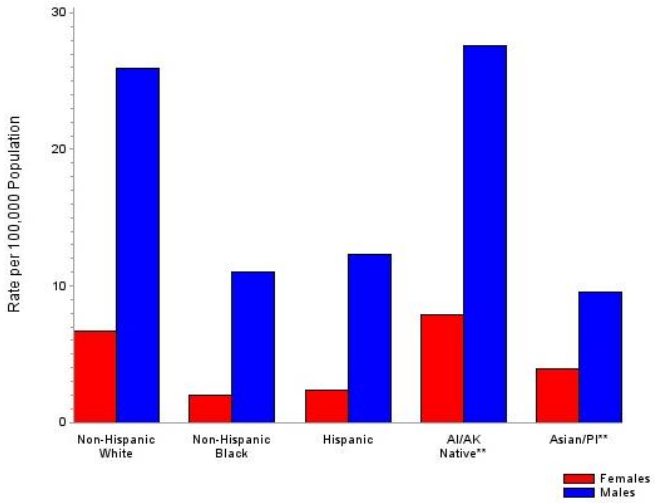


Source: CDC. Available at https://www.cdc.gov/mmwr/preview/mmwrhtml/su6001a11.htm.

Figure 10 illustrates that, as with all ethnicities, males in this population have even higher rates. One explanation for the high suicide rate may be that American Indian / Alaska Native young people are exposed to a high number of risk factors. Risk factors for youth suicide include a history of previous suicide attempts, a family history of suicide, a history of depression or other mental

illness, alcohol or drug abuse, stressful life event or loss, easy access to lethal methods, exposure to the suicidal behavior of others, and incarceration. Due to historical trauma, chronic poverty, and consequent alcohol and drug use and depression, American Indian and Alaska Native young people may be exposed to more of these risk factors than are members of other populations.

Figure 10: Suicide Rates Among Persons Ages 10 Years and Older, by Race/Ethnicity and Sex, 2005-2009.



Source: CDC. Available at http://www.cdc.gov/violenceprevention/suicide/statistics/rates02.html

LGBT Youth

Unlike age, gender, and race/ethnicity, which are relatively easy to determine among suicide decedents, sexual orientation and gender identify/expression may not be obvious to authorities or even known to family and

friends. There are no national statistics on LGBT suicides. Numerous studies have shown that LGBT youth are many times more like than heterosexual youth to report having attempted suicide, however, and this risk is even more pronounced for those who live in unsupportive environments. Anecdotal information suggests that LGBT youth are over-represented among those who complete suicide, as well. Bullying and lack of acceptance by family, friends, and institutions are widely thought to account to account for the greater risk of suicide among LGBT youth.

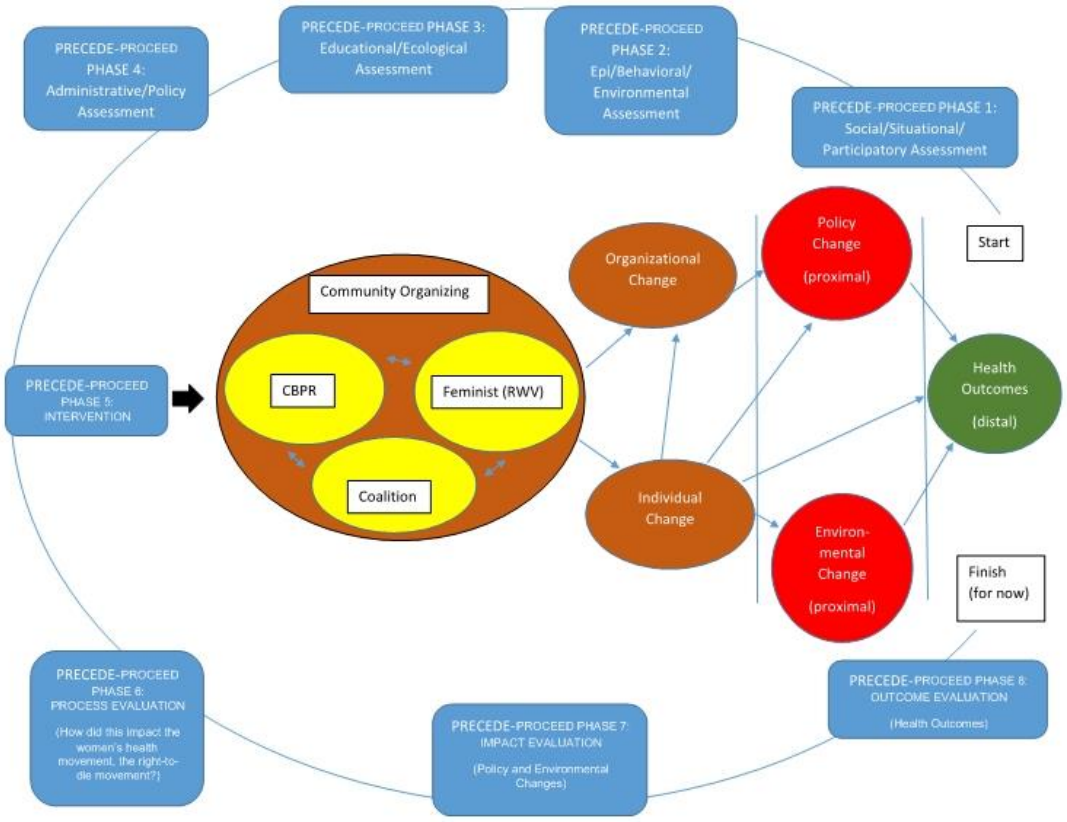
APPENDIX C:

HEALTH BEHAVIOR CHANGE: WOMEN AND END-OF-LIFE CARE

Health Behavior Change: Women and End-of-Life Care

Health behavior change has been researched extensively by public health advocates who have subsequently developed theories and models about how to effect change successfully. As a possible guide for women's health advocates interested in expanding and improving end-of-life options, including but not limited to aid in dying, I have developed a Precede/Proceed theoretical planning model and a logic model indicating one way women might consider integrating end-of-life issues into existing women's health organizations.

Precede/Proceed Diagram:



The Precede/Proceed model has eight phases:

Phase 1: Social Assessment, Participatory Planning, and Situational Analysis. The research conducted for this dissertation might serve as starting point for Phase 1, as I have conducted interviews with ten veteran reproductive rights veterans regarding their attitudes toward self-directed dying. As is indicated in the logic model, below, significant additional assessments would need to be undertaken by leaders of women's health organizations to determine whether, and in what ways, their constituents might be interested in addressing end-of-life issues.

Phase 2: Epidemiological, Behavioral, and Environmental Assessment. Through the research for this dissertation, I have preliminarily identified a health problem characterized by a lack of resources/control for individuals and their caregivers as the individuals approach the end of life and/or contemplate hastening death. I have also preliminarily identified possible environmental determinants and behavior patterns/social norms that decrease the ability of individuals to self-direct their own dying.

Phase 3: Educational and Ecological Assessment. I have preliminarily identified possible barriers to individuals being able to self-direct their dying as they see fit. Additional assessment by women's health leaders regarding knowledge, experiences, and desires of their constituents would be needed to

determine whether and how to move forward with an end-of-life health care and options campaign.

Phase 4: Administrative and Policy Assessment and Intervention Alignment. Based on my research, I have preliminarily identified some policy barriers to exercising autonomy regarding self-directed dying and have suggested ways to reduce these barriers and to facilitate self-direction at the end of life. Additional input from concerned advocates would be needed to plan a women's health campaign to improve end-of-life options.

Phase 5: Implementation. This phase would likely involve community organizing (drawing on Community-Based Participatory Research, Coalition-Building, and Feminist models such as "Raising Women's Voices"), on organizational change (especially in legislatures, courts, professional associations, and educational institutions), and on individual change.

Phase 6: Process Evaluation. This phase of evaluation would focus on whether/how the activities women's health advocates eventually undertook (if any) weakened, strengthened, changed, or had no impacted the women's health movement and the right to die movement.

Phase 7: Impact Evaluation. This phase of evaluation would examine how many institutional policies had been changed, and in what ways, and how many new environmental resources (information, services, and supportive social norms) had emerged.

Phase 8: Outcome Evaluation. This phase of evaluation would focus on health outcomes such as whether individuals seeking hastened death and/or individuals at the end of life experienced a decrease in physical and/or psychological distress and/or an increase in perceived quality of life; whether family caregivers experienced decreased stress and/or increased quality of life; and whether health care providers experienced less stress and greater efficacy in caring for patients at the end of life and/or wanting to hasten death.

The next page shows a logic model of one way women's health activists might develop an end-of-life movement including, but not limited to, aid in dying.

Our Bodies, Our Lives, Our Right to Decide

Possible Framework for Integrating End-of-Life Care and Self-Directed Dying into Women's Health Agendas and Activities

Community Outreach and Network Creation →

Engage women's health leaders at NWHN, NAWHERC, BWHI, RWV, etc. in reaching out to constituents to determine their levels of interest and areas of interest regarding end-of-life issues.

Establish network or collation of women's health leaders to share information and coordinate activities

Issue Selection/ Prioritization by Communities →

Possible Issue Examples:

Advanced Directives

Caregiver Support

Eldercare Services

Disability Support

Physician Aid in Dying Legislation

Death Midwifery Services

Public Education

Provider Education

Use CBPR and/or RWV models (interactive over time)

Possible Social/Political Activities →

Use models of community organizing to: 1) expand access to illegal and quasi-legal assisted dying; 2) lobby and/or advocate for legislative changes at the state and federal levels regarding: better care for the ill, disabled, and dying and their families, the repeal of assisted suicide laws, and the review/regulation by the FDA of "peaceful, reliable pills"

Use models of organizational change to encourage academic institutions and professional associations to prepare practitioners for a new role re: self-directed dying

Use models of legal change (including litigating) to challenge case law that punishes care providers who treat patients who hasten their own death

Possible Policy Outcomes →

Assisted suicide laws and default homicide laws repealed from criminal code unless suicide was manipulated or coerced

Physician assistance (including euthanasia for those who can't self-administer drugs) available in at least some circumstances (terminally ill adults and minors)

Non-physician assistance available through nonprofit associations or DIY

Controlled substance regulations changed to allow greater access to FDA-approved "peaceful, reliable pills," removing physicians as the only gatekeeprs

Advanced directive regulations expanded to include possible aid to patients with dementia based on directives made when they were competent

Revised standards of care promulgated by the APA and other professional associations, risk management entities, health care institutions, and case law to protect autonomy of adults who can make and understand decisions, and the providers who care for them (making possible the provision of more appropriate mental and physical health care for people considering hastening death, especially if not terminally ill; removing prior or current mental health diagnoses as a reason to deny any individual bodily autonomy or liberty unless his or her decisional capacity is clearly impaired).

Expanded government provision of (or support of community-based organizations that can provide) medical and non-medical (social) supports for people who are ill, disabled, elderly, and/or dying, and for their caregivers

Ongoing/expanded culturally appropriate support for meaningful interventions to prevent impulsive suicides, especially among the young

Possible Health Outcomes

↓physical and psychological distress for people wanting greater agency at the end of life and/or self-directed dying

↓psychological and social stress for family care givers of ill, frail elderly, and dying people (often women), as they will know what their loved one's want, will be able to access aid if desired, and may experience a shorter but higher quality time of togetherness during care giving

↓stress for doctors, as they will be better educated about how they can respond to requests for aid