

AUTONOMY, IDENTITY AND THE RIGHT TO DIE: A QUALITATIVE STUDY OF  
MEDICALLY ASSISTED DEATH ATTITUDES IN THE CANADIAN CONTEXT

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## ABSTRACT

In Canada, medically-assisted death has been legal since June 17<sup>th</sup>, 2016, when Bill C-14 received royal assent in the Canadian legislature. The legal proceedings around MAiD in Canada have been supported by non-governmental organizations and advocacy groups, for and against MAiD. The legalization of MAiD is the culmination of decades of organization and advocacy, supported by generally favourable public opinion. In this dissertation, the author develops a theory to explain why individuals increasingly identify with pro-MAiD beliefs. The study consequently makes two contributions to the sociological literature; 1) it reveals the connections between autonomy, care work, humanism, and pro-MAiD identities; 2) it features the development of a critical realist social psychology, focused on the reflexivity and the creation of personal moral identity.

Specifically, the study is focused on how lived experiences of death – including caregiving, bereavement, and/or serious illness, inform pro-MAiD beliefs for volunteers and other actors involved with pro-euthanasia organizations. The author theorizes that pro-MAiD identities are centred primarily on the principle of autonomy, which is couched within humanist and naturalist cultural frameworks, and enacted through care work. Specifically, over the course of care work, volunteers and other movement participants witnessed what they perceived as a fundamental loss of identity by the people for whom they were caring. The loss of identity witnessed by these carers motivated them to pursue greater autonomy over their own deaths, and to therefore avoid the deterioration they witnessed in others. It also motivated them to act as social carriers for the dissemination of norms associated with pro-MAiD political stances.

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## TABLE OF CONTENTS

Abstract .....	ii
Acknowledgements .....	3
Table of contents .....	iv
1: Introduction: the Sociology of Right-to-Die Beliefs .....	1
Dissertation Outline .....	8
2: The Context of Medically Assisted Death in Canada.....	9
The Decriminalization and Secularization of Suicide.....	10
The Development of Hospice, Palliative Care and Patient Rights' Movements.....	14
Patient Rights.....	18
The Sue Rodriguez Case and the Emergence of the Canadian MAiD Movement .....	21
Current MAiD Policy .....	23
Conclusion.....	26
3: Using Grounded Theory Method to Study Medical Assistance in Dying .....	27
Evolution of the Research Design and Questions.....	27
Qualitative Design .....	31
Using Grounded Theory Method to Study Medical Assistance in Dying.....	31
Why Grounded Theory? .....	37
Recruitment.....	39
Data Analysis .....	44
Evaluating Research Quality.....	52
Conclusion.....	55
4: Theoretical frame: Realist Social Psychology .....	57
On Social Psychology .....	57
Critical Realism .....	60
Tenets of Critical Realism: Analytic Dualism and Emergence .....	62
The Structural-Cultural Level .....	66
The Socio-cultural Level .....	70
The Personal Level.....	73
Conclusion.....	74

5: The Critical Realist conception of Reflexivity and the formation of personal identity	75
Reflexivity and Identity in Symbolic Interactionism.....	76
Reflexivity in Practice Theory.....	89
The Realist Conception of Reflexivity.....	95
Moral Identity and Morals .....	100
Conclusion.....	114
6: Euthanasia Beliefs and Autonomy .....	115
The Structural Organization of Mortality.....	117
The Cultural Organization of Mortality .....	122
Religion and Autonomy.....	127
Conclusion.....	131
7: Autonomy in the Pro-MAiD Movement: A Cultural Principle and its Moral Background.....	133
Autonomy and pro-MAiD Organizations .....	134
The Secular Humanist Moral Background of Autonomy .....	139
Metaphysical and Metaethical Assumptions .....	141
Grounding .....	144
Method of Argument .....	149
Conceptual Repertoires and Objects of Evaluation.....	154
Conclusion .....	157
8: Experiencing death I: Care and the Loss of Identity .....	159
Doing Care Work.....	163
Control over the Timing of Death.....	172
Early Death.....	173
The Prolonged Death .....	175
9: Experiencing Death II: Autonomy and Identity .....	180
Autonomy, Identity and the Good Death .....	180
The Bad Death: Losing Identity .....	184
The Aesthetic Self .....	184
The Physical Self.....	187
The Cognitive Self.....	190
The Loss of Social Identity.....	193
Conclusion.....	196

10: Conclusion.....	198
Research Question and Findings.....	198
Research Limitations.....	202
Theoretical Findings and Representativeness .....	202
Researcher Subjectivity .....	203
Retrospective Data .....	204
Pro-MAiD Only.....	204
Research Contributions .....	205
New Independent Variables .....	205
Gender and Care Experiences .....	205
Education and Humanism.....	206
(Dis)enchantment and the Sequestration of Death .....	207
Ethical Reflections .....	208
Critical Realist Social Psychology: A Prototype .....	209
1) The Causal Powers of Culture .....	211
2) The Causal Powers of Social Groups .....	212
3) The Causal Powers of Personal Properties .....	212
References.....	214
Appendix A: List of Secondary Documents .....	231
Appendix B: Evolution of the Research design and Table of Research Questions .....	234

## 1: INTRODUCTION: THE SOCIOLOGY OF RIGHT-TO-DIE BELIEFS

In 2015 the Supreme Court of Canada struck down laws prohibiting medical assistance in dying (MAiD).<sup>1</sup> A year later, Bill C-14, the Medical Assistance in Dying Act, passed through parliament. These changes to Canada's criminal code, to allow physicians and nurse practitioners to actively help their patients die, were in step with Canadian public opinion, which has, over the past sixty years, become more favorable to physician assisted suicide for the terminally ill and suffering.<sup>2</sup> Nevertheless, there remain ambiguities in the legal status of assisted dying, as aspects of the legislation, for example the idea that people should be approved for MAiD only in cases where death is "foreseeable," have been criticized for being too vague (Harris 2016), which can lead to delays or complications in approved cases (Grant 2017). As a result, the struggle over MAiD continues, as terminally ill people and their families navigate a shifting legal landscape, often with the help of advocacy organizations.

Moreover, Canadians' attitudes and values are complex – their beliefs, especially regarding personal autonomy, continue to come into conflict with aspects of Canada's MAiD legislation, and raise fundamental questions about agency and selfhood. For example, while

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<sup>1</sup> In general, euthanasia refers to the practice of ending a person's life to cease suffering (offering a good death). There are different qualifiers for euthanasia. Active euthanasia refers to the administering of a substance or other act to end life, while passive euthanasia refers to the withdrawal of treatments or basic nutrition and hydration to hasten death. Euthanasia can be voluntary, meaning the person consents to it, or involuntary ("mercy killing"), where no clear consent is given, or the wishes of the person are unknown. In general, MAiD falls under the category of voluntary, active euthanasia, although if the lethal substance is self-administered, it is sometimes called "assisted suicide." To avoid confusion, I use the term "medical assistance in dying," as this is the language adopted by the Canadian government to describe the practices that fall under the rubric of legal, voluntary hastening of death.

<sup>2</sup> While in 1953, only 44 percent of surveyed Canadians approved of the practice (1953. "Canadian Gallup Poll, May 1953. #227." edited by G. C. Inc.), that number had doubled by 2014 (2014. "Most (84%) Canadians Believe a Doctor Should Be Able to Assist Someone Who Is Terminally Ill and Suffering Unbearably to End Their Life." Ipsos-Reid.).

medical assistance in dying is now legal, the current policy requires that people accessing it be competent on the day of the procedure. Essentially, documents known as advanced directives – living wills that specify the conditions under which a person no longer wishes to remain alive – do not have legal status, which means that for people who suffer from dementia, MAiD is not a possibility. While this is a definite policy problem, it also raises interesting sociological questions about conceptions of personhood and autonomy. For example, when is the dementia sufferer no longer a legal person, capable of exercising agency? Indeed, questions of autonomy, what it is, when it should be exercised, and by whom, lie at the heart of pro-MAiD attitudes in Canada.

Despite a significant literature on euthanasia attitudes, the sociological understanding of Canadians' experiences, and especially, how those experiences interface with belief in autonomy principle, remains limited. This is a problem, from both a policy and an ethical perspective. In the first place, it is difficult to craft legislation that meets the needs of the concerned without a sound understanding of the lived experiences of the dying, their families, and those who advocate on their behalf. While public consultation is an important tool for policy makers, a more academic, sociological view on euthanasia provides a picture of the social forces driving a moral shift in Canadian society. Secondly, the dearth of in-depth, micro studies on euthanasia attitudes leaves us with few explanations of why structural factors seem to have the impact they do, for example, why, in some jurisdictions, more educated people tend to support euthanasia; in such cases, we must rely on folk-psychological or sociological explanations that do little to clarify how the experience of social forces shapes people's moral views of voluntary euthanasia.

Consequently, the study of medically-assisted death presented here began with the assumption that sociology can contribute to a better understanding of attitudes towards



medically-assisted death in the Canadian context. At its core, this work is inspired by a “naturalistic” (Johnson 2014:1) or “humanistic” (Fromm 1947:6) view of ethics, one in which morals are based on the socio-historical conditions of human life. To echo Erich Fromm: “good in humanistic ethics is the affirmation of life.” (Fromm 1947:20). Life, in Fromm’s view, has its own intrinsic potential for growth and productiveness, a developmental capacity that should be encouraged. The task of the social sciences, for Fromm, is to uncover humans’ basic social and psychological needs. Once these needs are revealed, it becomes possible to develop an ethical position, since one is in a better position to evaluate and assess social configurations based on how they meet basic needs.

There is a social psychological corollary to humanistic ethics, one that goes back to Marx’s statement that “Consciousness is, therefore, from the very beginning a social product, and remains so as long as men exist at all.” (Marx 1978:158). Ethical consciousness, taking a moral stand on one issue or another, is, like other kinds of consciousness, bound to the social order in which it originates. Yet, the contribution of social psychology is the recognition that consciousness is traceable not only to its external material conditions – social structure, but additionally to the way those external conditions are organized, mediated and negotiated by people as they exercise agency in their lives. Any humanistic study of ethics must address the process through which external forces are reflexively appraised by groups of social actors. In this way, we can reconstruct the causal chain, from social structure, to cognition to action, back to social structure. Again, this exercise is not simply academic. It accomplishes two practical ethical goals: 1) it facilitates understanding of how existing ethical frameworks fulfill the needs of concrete social actors (or how those social actors *imagine* the ethical frameworks fulfill their

needs); 2) it raises the possibility of asking whether a given ethical position or concrete policy *really* fulfill those needs?

Thus, one of the purposes of this dissertation, in epistemological terms, is to lay some of the groundwork for a sociologically grounded MAiD ethics. In the study presented in these pages, I undertake the first part of this process: an analysis of the pro-MAiD perspective, and its roots in the life experiences of the individuals involved in the movement. As for ethical recommendations, these are left for future works. When it comes to medically-assisted death or medical assistance in dying (MAiD), sociology can contribute to an understanding of the social forces that led to its majority acceptance and eventual legalization. To what end? In the first place, revealing the social forces behind the rise of MAiD, potentially contributes to the development of a humanistic (in Fromm's sense) ethical framework in which to approach the issue; if one understands the social reasons that led to the adoption of pro-MAiD points of view, it becomes easier to understand the ethical dimensions of MAiD and its implications for society. But more important than this retroactive moral appraisal is the potential benefit of a social understanding of MAiD to the current problems faced by courts, health care practitioners, medical institutions and individuals who are contemplating MAiD for themselves or their loved ones.

Consequently, in this dissertation I advance a sociological analysis of pro- MAiD identity as it is displayed and managed through support for MAiD. Support here is broadly defined: the study is about people who in some way engage with the MAiD debate – whether through keeping informed about legal developments, subscribing to newsletters about MAiD, participating in informal or formal advocacy, or simply maintaining personal advanced care directives and spreading the word about such activities to friends and family. Through their pro-

MAiD activities, individuals navigate and negotiate the social conditions surrounding MAiD. Additionally, this navigation and negotiation is reflexive<sup>3</sup>: not only do people act under the social conditions around MAiD; they actively think about the contexts in which they find themselves, and, through intensive reflection on those contexts, craft pro-MAiD identities and narratives. One of the primary tasks of this work was to study those identities, with the goal of identifying the social forces responsible for the emergence of pro-MAiD attitudes from the micro to the macro level.

The other main task of the dissertation was to advance a realist social psychology. Thus, while the dissertation takes the form of an empirical work, its purpose is also to demonstrate how critical realism can be used to understand moral changes in society. For this reason, a significant amount of time is spent in early chapters developing the critical realist framework, and realist conceptions of structure, culture, reflexivity and identity. Not only are these components major parts of the theoretical sensitivity guiding the grounded theory; they are also important in their own right as contributions to realist social theory more generally.

This dissertation relies on the concepts of identities and narratives. Although the concept of identity will be discussed further in the theoretical frame chapter, it is necessary to introduce it briefly here, and distinguish it from the concepts of narratives and norms. While the framework I adopt in this dissertation is realist, my conception of identity is synergized from symbolic

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<sup>3</sup> Margaret Archer provides a useful definition of reflexivity: “the regular exercise of the mental ability, shared by all normal people, to consider themselves in relation to their (social) contexts and vice versa.” Archer, Margaret. 2012. *The Reflexive Imperative in Late Modernity*. Cambridge: Cambridge University Press. P. 1 Archer distinguishes between what she calls “universal reflexivity” – the natural human capacity to think about circumstances – and the intensive reflexivity of the “reflexive imperative,” which she sees as being a product of modernity. In this dissertation, I use the concept of reflexivity to refer to universal reflexivity. In the theoretical frame chapter, I discuss the differences between the realist, symbolic interactionist, and practice theory concepts of reflexivity.

interactionism and Archer's realism. Essentially, identity refers to the set of meanings attached to oneself as an object. We can think of identity as the answer to the question: who am I (in this time, space, era, family, group, place, and so forth)? Identity matters because it is the continuously updated product of reflections on past experiences – more fundamentally, it is the set of meanings that make biographical reflexivity possible, since all reflections on context happen through the lens of the most basic set of meanings locating a person to his or her self.

Narratives are accounts of events that have a time dimension and meaning to the narrator. They can be about real objects or fictional ones. In this dissertation, much of the data is in narrative form. The interview technique used to find out about personal identity was focused on eliciting stories and statements about MAiD and life experience. Thus, the data consisted primarily of the meaning that MAiD had for the person being interviewed. For the people interviewed, MAiD was embedded in their life experiences. Each person understood MAiD through her or his own personal lens, one inseparable from life experiences and the meanings of these experiences. Often the connection between MAiD and life experiences took a narrative form – it was presented in anecdotes, many of which are recounted in later chapters.

Identities, and narratives about those identities, are products of agency exercised under conditions of constraint and enablement. To analyse identity, then, is to “reverse engineer” it, to attempt to reconstruct the process by which it came to be. Through this reconstruction, the analyst can identify social constraints and enablements as they shape agents' reflexive construction of identity. In the case of pro-MAiD identity, preliminary research showed that support for MAiD was connected to people's life experiences of death. That is, the people who supported legal MAiD tended to do so in the context of personal accounts about the deaths of family members or friends. The research question for the study then became, how is the pro-

MAiD identity shaped by experiences of death and bereavement?<sup>4</sup> Answering this question reveals the ways that, through the experience of death, individuals make sense of the social conditions of their own mortality. Such a view in turn reveals conditions that might, when investigated through quantitative, theory-testing research, turn out to be shared, social conditions contributing to the emergence of pro-MAiD identity.

Based on the analysis of in-depth interviews and secondary documents and accounts related to MAiD in Canada, I propose that the MAiD identity is organized primarily around conceptions of the value of human autonomy. Furthermore, and more importantly, these conceptions of autonomy are informed jointly by humanistic or naturalistic world-views, and by sympathetic connections to dying others under the care of pro-MAiD people. Specifically, for people who identify as pro-MAiD, their humanist beliefs are confronted with the degradation and loss of identity in another person. Given the humanist beliefs, autonomy is the logical response to this problem. By pursuing autonomy, they hope to avoid the loss of their own identities.

The empirical argument in this dissertation is connected to another, broad theoretical demonstration of the utility of critical realism in social psychology. Specifically, while focusing on theorizing the formation of MAiD identity in the life experiences of social actors involved in the movement, I also demonstrate how critical realism can be used to understand social change. Although the dissertation deals mainly with the formation of identity at the personal level, this identity formation is to be understood in the context of the increase in public support for MAiD. Consequently, the theoretical frame and its operationalization offered here are prototypes to a critical realist social psychology, one that could be used to analyze any number of social changes

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<sup>4</sup> See Appendix B, which includes a list of research questions. In grounded theory method, research questions emerge over the course of the study.

– for example the rise of right-wing nationalism or the adoption of neo-liberal economic principles – from a critical realist angle.

### *Dissertation Outline*

In what follows, I discuss autonomy, and its role in the construction of the pro-MAiD identity for individuals involved in the pro-MAiD movement. In Chapter 2, I discuss the historical context of the MAiD movement in Canada, which finds its roots in the decriminalization of suicide, and the patients' rights and palliative care movements. The overview also includes a discussion of the legal history of MAiD in Canada, as well as a discussion of the legality and process of MAiD today. In Chapter 3, I turn to grounded theory and its usefulness in the study of MAiD identity. In Chapter 4, I discuss critical realist epistemology and ontology. Chapter 5 is focused on the extension of realist epistemology and ontology in social psychology, especially around the concepts of reflexivity and identity. In Chapter 6, by way of a review of the sociological literature on MAiD beliefs, I provide important background to the concept of autonomy and its source in the disenchantment of death. In Chapter 7, I begin to discuss how autonomy figures in the pro-MAiD movement and its secular humanist moral background. In Chapter 8, I take up the question how the life experience for caring for dying people shapes people's understanding and narrative use of autonomy. In chapter 9, I discuss how autonomy is tied to the conception of the bad death and the idea of losing identity. Chapter 10 serves as a conclusion.

## 2: THE CONTEXT OF MEDICALLY ASSISTED DEATH IN CANADA

In the past half century, MAiD has surfaced as a major legal and political issue around the world. At the time of writing, some form of assisted death is legal in Belgium, the Netherlands, Luxembourg (the “Benelux” countries), Norway, Switzerland, Uruguay, Colombia, Norway and in eight US states (Societies). Proposals for legalization of MAiD have also been tabled in the legislatures of other countries, such as the U.K. (Harty et al. 2018). In Canada, MAiD has been legal since June 17<sup>th</sup>, 2016, when Bill C-14 received royal assent in the Canadian legislature. Bill C-14, which includes amendments to Canada’s criminal code, creates exemptions to criminal code articles pertaining to homicide, suicide and “the administering of a noxious thing.<sup>5</sup>” It also sets out guidelines, procedures and safeguards, as well as establishes a legal environment where MAiD is permitted, regulated and monitored.

The changes to the Canadian criminal code represent concomitant changes to the normative landscape of death, especially the emergence of the idea that people should be in control of their own deaths. Although this idea itself, especially its background in humanism, will be discussed in Chapter 6, in this chapter I offer a sketch of the historical forces leading to the enshrining of the principle in law. The legalization of MAiD, both by the Supreme Court’s

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<sup>5</sup> Canada’s criminal code contains express articles prohibiting the administering of poison or any other substance (a “noxious” or harmful substance) to another person. After the passage of Bill C-14, the exemptions to criminal code article 245 read as follows: “Exemption -- (2) Subsection (1) does not apply to (a) a medical practitioner or nurse practitioner who provides medical assistance in dying in accordance with section 241.2; and (b) a person who does anything for the purpose of aiding a medical practitioner or nurse practitioner to provide medical assistance in dying in accordance with section 241.2 [,]” where section 241 is the section pertaining to suicide.

decision and the passage of Bill C-14, codifies the autonomy principle as it applies to medical assistance in dying, in that the Supreme Court, by finding in favour of Carter in the landmark case, has upheld the right of persons to end their own lives as they see fit (with some restrictions). Yet, legally and normatively, such a right is a historical product, in that it gradually emerged through a variety of legal and normative changes regarding death, suicide and the rights of patients generally. Consequently, the legalization of MAiD, and the centrality of the autonomy principle in the pro-MAiD identity, is best understood historically in the context of three factors: 1) the secularization and decriminalization of suicide, 2) the development of the hospice, palliative care, and patient rights movements, and 3) precedent cases in the United States and Canada. In this chapter, I discuss these three factors, as well as the current MAiD process in Canada.

### *The decriminalization and secularization of suicide*

The legalization of medically-assisted death is the culmination of a long legal struggle that began in the early twentieth century and has its roots in the normative and legal separation of suicide from medically-assisted death. Suicide itself has a complicated history in Western society. In Ancient Greece, there was some tolerance for suicide: aristocratic ancient Greek culture emphasized virtue and living well – if suicide was done to prevent living in a state of decline or dying poorly, it was considered acceptable (Butler et al. 2013). This is not to say that suicide was cast in terms of autonomy; rather, suicide itself had a number of meanings, ranging from concerns around quality of life, to honour, to the pursuit of truth.<sup>6</sup> There is also evidence

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<sup>6</sup> Note, for example, Plato's account of Socrates' trial, presented in *Apology*. Socrates decides to employ his usual method of truth-seeking and risk the death rather than adopt a defence that he might have seen as too close to "sophistry". Upon hearing his sentence, death, he says, "You would have liked to hear my weep and wail, doing and saying all sorts of things which I regard as unworthy of myself, but which you are used to hearing from other people. But I did not think then that I ought to stoop to servility



that assisted suicide and even voluntary euthanasia were tolerated in Ancient Greece and Rome (Dowbiggin 2007:8). With the emergence of Christianity in the 2<sup>nd</sup> and 3<sup>rd</sup> centuries CE, however, the culture around suicide changed, and prohibitions against suicide became prevalent. In *City of God*, for example, Augustine “argued that suicide was simply another form of homicide, and thus was both a crime and a sin prohibited by the sixth of the ten commandments.” (Dowbiggin 2007:14) Later, in his influential teachings, Thomas Aquinas emphasized that to kill oneself was to interfere with God’s will. By the beginning of the nineteenth century however, advances in science and medicine raised ethical issues that called into question the moral and legal prohibitions against suicide, at least in the context of medical care.<sup>7</sup> These issues centred on the idea of “quality of life” and the right to determine when “it was acceptable to cease living.” (Butler et al. 2013). For example, amongst the British working class there is evidence that “living people might legitimately exert control over the timing and manner of departure of those who were dying from this world, and that it was possible to either delay or expedite the event as circumstances required.” (Frisby 2015:109).

In Canada, there is little evidence about popular views from the eighteenth and nineteenth centuries on hastening death related to suffering from illness. Evidence does exist, however, that developments in the moral and legal frameworks within which people viewed suicide in general set the stage for the push for legal MAiD that would occur in the latter half of the twentieth

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because I was in danger, and I do not regret now the way in which I pleaded my case.; I would much rather die as the result of this defence than live as the result of the other sort. (...) In battle it is often obvious that you could escape being killed by giving up your arms and throwing yourself upon the mercy of your pursuers; and in every kind of danger there are plenty of devices for avoiding death if you are unscrupulous enough to stick at nothing. But I suggest, gentlemen, that the difficulty is not so much to escape death; the real difficulty is to escape from doing wrong, which is far more fleet of foot.” Plato. 1969. *The Last Days of Socrates*. Translated by H. Tredennick. London: Penguin Books. P. 73. For Socrates, it is better to die in accordance to a universal truth than it is to live but compromise that truth.

<sup>7</sup> Durkheim’s publication of *Suicide* also represents a rethinking of suicide, since Durkheim retheorizes suicide as a social fact rather than a personal trouble or personal moral failing.

century. The earliest evidence on popular views towards suicide comes from mid-nineteenth century Ontario, where suicide was a “malleable metaphor” (Miron 2014:576). In popular discourse, suicides were considered the result of any number of personal moral failures, from poverty, to sexual impropriety to alcoholism. This view had its roots in the Christian view of suicide as a sin: suicide was taken to be evidence of moral deterioration in the individuals, families and groups in which it occurred.

By the latter half of the nineteenth century, however, Victorian Ontario was moving towards decriminalization and secularization of suicide, and a concomitant loosening of the normative judgements about it. The laws on suicide were provided by English common law and provincial statutes. In English common law, the legal writings of William Blackstone established an important exception to the notion of *felo de se* or literally “being a felon against oneself,” which stipulated that people who killed themselves in a state of mental instability were to be excused from the charge of suicide (Miron 2014:583). Thus common law provided an important counterweight to provincial criminal law, under which suicide was equated with homicide and was punishable by “the forfeiture of goods, chattels, lands and tenements.” (Miron 2014:583). The penalty for convicted suicide effectively severed a dead person’s beneficiaries from their inheritance, and thus, in principle, established a powerful disincentive. In addition to the material penalty, until 1892, the bodies of those who killed themselves were supposed to be staked, displayed and buried under the road – in other words, desecrated and denied the rite of Christian burial, the lack of which imposed an eternal, spiritual penalty on the deceased (Miron 2014:583).

In 1892, suicide was removed as a statutory offence from the criminal code. Yet, it was still recognized as murder under common law<sup>8</sup>, and attempting or assisting suicide was still a

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<sup>8</sup> In the Canadian Legal System, there is a distinction between common law and the criminal code. Common law refers to the set of legal decisions in the English royal court that serve as a

serious criminal offence (Miron 2014:583-84). Nevertheless, the customary legal practice, starting in the late 1890s, most suicides in Ontario during this time were not found to be criminal, but rather, were deemed the result of mental illness, which was beyond the control of the person who killed themselves (Miron 2014:591).<sup>9</sup> In sum, although suicide remained morally wrong to nineteenth-century Ontarians, (Miron 2014:579), the loosening of legal penalties in cases of mental illness marked an important change in how the law and how society viewed suicide. Despite this, suicide and attempted suicide were not decriminalized federally until 1972<sup>10</sup> (Ogden 1994b). The developments in Ontario in the late nineteenth century represent a divergence in conceptions of killing oneself from the classical Christian concept of suicide. Namely, the idea that self-killing could be a result of causes other than moral failure opened the door to new ways of thinking about suicide.

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precedential framework for the legal systems in former British colonies and the UK. In Canada, common law is used in all provinces except for Quebec. The Criminal Code of Canada, on the other hand, is a statute enacted by parliament in the Constitution Act of 1867, that sets out “types of conduct that constitute criminal offences but also establishes the kind and degree of punishment that may be imposed when an individual is convicted of an offence.” In 1953, the Criminal Code was consolidated to “[abolish] all common law offences (i.e. those created by case law rather than by a statute) while preserving common-law defences, justifications and excuses.” Pringle, Alexander. 2006. "Criminal Code." in *The Canadian Encyclopedia: Historica Canada*.

<sup>9</sup> Convictions for attempted suicide continued until the late 1800s Miron, Janet. 2014. "Suicide, Coroner's Inquests, and the Parameters of Compassion in Ontario, 1830-1900." *Social History* 47(95):577-99.

<sup>10</sup> Aiding someone else to kill themselves remained a criminal offense until the 2016 passage of Bill C-14, which amended the criminal code to make exceptions for medical professionals or others who would help someone legally end their lives. The prohibition on assisting someone to kill themselves was an important contextual element in the development of a pro-MAiD movement, since while the prohibition stood, it imposed a threat to the safety and well-being of people who helped others kill themselves.

### *The Development of Hospice, Palliative Care and Patient Rights' Movements*

While the changes in popular and legal views on suicide were an important background factor to the development of a robust conception and movement towards MAiD in Canada, they were relatively tangential to the concrete practice of ending one's own life in the context of prolonged medical care. The development of legal MAiD required a more direct revolution in the conception of death in medicine, which would not occur until the twentieth century. The movement in favour of the legalization of medically assisted death is historically preceded by several distinct but intertwining social movements that changed the way that death was managed and approached by medical professionals, governments and the lay population. Firstly, the palliative care movement recalled the medical profession to its traditional role of caring for, rather than only curing, the dying. The hospice movement, originating in the Christian *hospitaller* orders and directed towards the charitable care for the sick, the poor, the disabled, travellers and others who could not work, emphasized the holistic, spiritual nature of death. Finally, the patients' rights movements introduced the idea of patient autonomy into the medical field, challenging physician authority over patient care. Like the changes to suicide laws, these social movements, in the Canadian context and elsewhere, set the stage for the development of a robust movement towards the legalization of medically assisted death.

Although palliative care is sometimes cited as a reason why medically-assisted death should not be legal, the historical development of palliative care represents a significant change in the way that death was managed in the twentieth century. Palliative care physicians themselves have been somewhat divided on whether they should provide MAiD. In 2015, the Canadian Society of Palliative Care Physicians (CSPCP) conducted a survey among its members: 73 per cent were opposed to the legalization of MAiD (Proudfoot 2017), holding

opinions that appear to be at odds with the majority of the Canadian population. After the legalization of MAiD, only 8 per cent of palliative care physicians reported providing MAiD to patients under their care (2018c), suggesting that palliative care physicians typically do not provide MAiD, albeit with some exceptions (Proudfoot 2017). Additional CSPCP reports on MAiD also reveal some of the concerns of palliative care physicians about legal MAiD – primarily that the legalization of medically assisted death will lead to a disinvestment in palliative care research, and an under-provision of care to suffering patients, which will in turn cause people to access MAiD prematurely:

The Canadian Society of Palliative Care Physicians strongly recommends measuring, monitoring, and reporting about the availability of alternatives such as palliative care, social services, and respite. These resources and expertise can mitigate suffering. If alternatives are not offered to patients and families – or they are not available – people may opt for MAiD by default. (Taylor 2018).

This argument is also sometimes marshalled by opponents of MAiD, some of whom see the increase in demand for MAiD as the result of inadequate resources directed towards long-term care, including palliative care:

Provided they can consent, people with disabilities such as rheumatoid arthritis and paraplegia, or those with mental health difficulties could qualify for assisted dying according to the criteria set down by the courts. Often people who have these challenges are struggling in a world with many barriers. The danger is that they will choose assisted death because of the failure of our society to provide the necessary support. Through increased access to palliative care, disability, chronic disease, and mental health services, Canada can significantly reduce the number of people who see death at the only viable option to end their isolation, their feeling of being a burden, and their sense of worthlessness. (Larry Worthen, Special Joint Committee on Physician Assisted Dying, February 3<sup>rd</sup>, 2016)

Despite the ambivalence of the palliative care profession towards MAiD, as well as the status of palliative care in anti-MAiD arguments, the development of palliative care, like the easing of norms around suicide, opened up both the process of dying and issues of quality of life under intensive medical care to broader questioning.

In some ways, the history of the professionalization of medical practice is the history of the progressive shift from palliative to curative medicine. Palliation is “a form of treatment that seeks to alleviate symptoms of a disease without expecting to cure it.” (Duffin 2014:206) In Europe, until the eighteenth century, physicians defined illness and disease based on the patient’s subjective report. Diseases were “defined as constellations of symptoms,” and physicians focused on alleviating those symptoms (Duffin 2014:206). By the nineteenth century, however, advances in anatomy had made possible an “anatomical-clinical” orientation in medicine, where diseases were defined based on physical defects. Diseases were recast as the underlying cause of subjectively reported symptoms, and increasingly, seen as curable through surgery or other interventions (Duffin 2014:207). The consequences of the anatomical clinical approach were that through the twentieth century, specializations in medicine were focused on “saving lives,” rather than alleviating symptoms, especially through dying (Duffin 2014:209).

Despite nineteenth and twentieth-century medicine’s emphasis on curing diseases, there was a persistent, yet limited, interest in palliation. Leading thinkers in palliative care, like William Osler (1849-1919) and Alfred Worcester (1855-1951), wrote about the dying process, and how best to ensure the comfort of those who were undergoing it (Duffin 2014:208-09). Nevertheless, it was not until the 1960s that palliative care became professionalized in the UK and North America. In 1967, English physician (and former nurse) Dr. Cicely Saunders founded St. Christopher’s Hospice in London, a hub for professional palliative care. Saunders also published over 30 articles on palliative care between 1958 and 1967, and visited hospitals in the United States, helping to professionalize palliative medicine in Britain and North America (Duffin 2014:210).

Contemporaneously to Saunders, psychiatrists began to investigate the psychological dimensions of death. British psychiatrist John M. Hinton conducted a study on dying in 1964, where he compared the psychological experiences of 204 patients, half of whom were expected to survive and half of whom had a negative prognosis. Hinton noted that the dying patients fared worse psychologically, and consequently, “recommended more attention to care of the dying and greater frankness and cultural sensitivity in communication over their needs.” (Duffin 2014:210). A few years later, in 1969, Swiss psychiatrist Elizabeth Kubler-Ross published her landmark *On Death and Dying*, which revolutionized palliative care. Kubler-Ross’ description of the psychological stages of dying (denial and isolation, anger, bargaining, depression, and finally, acceptance (Kubler-Ross 2005)) provided palliative care practitioners with a formal model that placed the needs of the dying person at the centre of medical practice (Duffin 2014:211).

Saunders’ and Kubler-Ross’ approach to care came to Canada primarily through the work of Dr. Balfour Mount, a urological cancer surgeon. Mount read and was heavily influenced by Kubler-Ross’ book, and visited St. Christopher’s Hospice to discuss palliative care with Dr. Saunders. After his trip, Mount founded Canada’s first palliative care centre, the Royal Victoria hospital in Montreal (Duffin 2014:212). In central Canada, Dr. David Skelton founded palliative care wards at St. Boniface Hospital in Winnipeg and at Edmonton General Hospital (Duffin 2014:214). Palliative care units were founded in Halifax and Toronto in the early and late 1980s, respectively. In the 1990s, the Canadian Hospice and Palliative Care Association, and the CSPCP were founded (Duffin 2014:215).

The development of palliative care drew the medical gaze back to the experience of the dying patient and opened an intellectual space where the needs of the dying person could be considered. Although key thinkers in the palliative care movement like Mount and Kubler-Ross

were against euthanasia, palliative care itself represents a movement towards a version of death where the dying person's needs are accommodated. Furthermore, Hinton's and Kubler-Ross's contributions mark the entrance of psychosocial concerns into the study of death. Whereas Osler concluded, after his study of 500 dying patients at John's Hopkins, that the symptoms of the dying were "worse to observe than to suffer" (Duffin 2014:209), Hinton and Kubler-Ross shed light on the potential psychological anguish of a poor death. Kubler-Ross also expanded her analysis to the patient's family, noting, in her extensive chapter on the subject, that "If members of a family can share these emotions [grief around separation] together, they will gradually face the reality of impending separation and come to an acceptance of it together." (Kubler-Ross 2005:154). Her observations here demonstrate that the new palliative care was concerned with the multi-dimensional nature of death, acknowledging its physiological, psychological and social aspects, especially as these played out in the changing relationships between dying people and their families and friends. Anselm Strauss' highly influential *Awareness of Dying* also made some important contributions on this front, revealing the social order of the intensive care unit and its impact on the dying patient (Strauss and Glaser: 1965). Thus, whereas in the nineteenth and early-twentieth century the medical focus in death was on prolonging life, the development of the palliative point of view by the mid-twentieth century signalled a return to easing the patient's passing, physically, psychologically, and socially. This renewed focus on the patient's experience of dying created the space for patient concerns, including their wishes regarding the timing and manner of death, to enter the medical space.

### *Patient Rights*

While the changes in how people thought about suicide, as well as the emergence of palliative and hospice care, were important preconditions to the emergence of a pro-MAiD



movement, the emergence of the patient rights movement was a more direct pre-condition to the concept of being in control of death. Given the prevalence of the anatomical-clinical model of medicine, the notion of patient autonomy signals a return to ancient Greek and Roman attitudes towards physicians, who were then expected to follow the orders of their patrons, even to the point of providing the substances for suicide (Dowbiggin 2007:10). The defining characteristic of modern professional medicine has historically been “clinical autonomy” (Armstrong 2002:1771), or the prerogative of the individual physician to diagnose and treat his or her patients. Yet, by the end of the twentieth century, clinical autonomy was being challenged by an emerging patient rights or patient autonomy movement.

The patient autonomy movement (PAM) emerged out of the American civil rights movements in the 1960s and 70s. These movements shared a number of principles, focused around a critique of professional, white, and male authority in a number of spheres, including politics, law, the family, the military, academia, and medicine. Among these principles were anti-paternalism, a rejection of the principle of “beneficence” – where professionals were to be trusted to act in the best interests of those seeking their services – and the idea that the constituents of social movements had a right to define their own interests and well-being (Rothman 2001:256).

In medicine, the PAM was spearheaded by lawyers, who, through lawsuits and other legal measures, pushed for the development of formal procedures governing the patient-physician relationship, especially the idea of “informed consent” for treatments (Rothman 2001:256). The PAM culminated in the Karen Ann Quinlan decision, one of the most important legal cases for the PAM itself (Rothman 2001:259) and for the MAiD movement more specifically (Butler et al. 2013). Karen Ann Quinlan, an American woman, fell into a coma after

consuming alcohol and drugs. Although her parents signed a release form allowing her physicians to remove Quinlan's respirator (claiming it was causing her physical pain), the hospital directors refused to honour their request. Following a lengthy legal battle, which resulted in the New Jersey Supreme Court issuing an order to the facility where Quinlan was receiving care, her respirator was removed, and she died ten years later, in 1985 (Butler et al. 2013). The Quinlan decision changed the balance of power between patients and physicians, as it placed more authority in the hands of patients and their families regarding treatment decisions:

The event that signals the movement's arrival, that announces and promotes a fundamental shift in the doctor-patient, or hospital-patient relationship, the point after which there was no going back to the old models of paternalism, comes from the legal forum in the guise of the Karen Ann Quinlan decision. In its aftermath came not only a new insistence on legal forms (to this day, lawyers oversee the signing of more advanced directives than doctors) but a shift in attitude to a "we": "they" patient mentality, as in: don't let them, that is, doctors and hospitals, do to me what they did to Karen Ann. Arguably, if one had to choose just one document to represent the triumph of the autonomy movement, that document would be a court decision, and it would be the Quinlan decision. (Rothman 2001:258)

The PAM had other important effects that changed the face of health care and the physician-patient relationship. These changes also established a context where the MAiD movement could find resonance. First of all, the PAM moved the relationship between patient and physician into a consumerist model: physicians were increasingly seen as providing a service (especially in the US, where basic medical care is a private good). Second, the PAM led to a diffusion and proliferation of medical information, which allowed patients to learn about treatments and medications on their own, and request that physicians provide the desired prescription or procedure. Finally, and as a consequence, the general expertise of physicians was called into question, since information, some of which contradicted physician narratives about a given medical treatment or diagnosis, was readily available (Rothman 2001:259-61).

In sum, the PAM eroded some of the professional authority exercised by physicians over the course of the twentieth century, and created a space for patients to make their concerns about medicine known and heard. Because of the PAM, patients could expect to exercise their will over important treatment decisions, up to and including the withdrawal of treatment, and more recently, the provision of MAiD.

*The Sue Rodriguez Case and the Emergence of the Canadian MAiD Movement*

Taken together, new views on suicide, and the emergence of the palliative, hospice and patient autonomy movement laid important groundwork for the legalization of MAiD. Spurred on by growing awareness of MAiD in the United States, three organizations emerged in Canada over the course of the 1980s and 1990s: Dying with Dignity Canada, Right to Die Canada, and l'Association québécoise pour le droit de mourir dans la dignité (AQDMD). These organizations were relatively marginal, until the MAiD movement galvanized around the emergence of publicized assisted dying practices and cases in the early 1990s (Ogden 1994a:40-52). Russell Ogden's landmark thesis (Ogden 1994a) provides an inside look at the practice of assisted death in the AIDs community in British Columbia. According to Ogden, by the early 1990s there was already anecdotal evidence that AIDs sufferers were seeking out clandestine assisted deaths (Ogden 1994a:74). In 1991, the Canadian AIDs Society argued that "incurably ill AIDs patients should be permitted 'to choose death as their next form of treatment.'" (Ogden 1994a:84). Along with cases of assisted deaths in the HIV/AIDs community, there were also several well-publicized cases of terminal-illness related MAiD, chief among them the Sue Rodriguez case.

Rodriguez's story is well-documented, especially in Hobbs Bernie (Hobbs Bernie and Rodriguez 1994) and (Martin 2016), so it will only be discussed briefly here. Sue Rodriguez

partnered with Right to Die Society founder John Hofsess<sup>11</sup> and MP Svend Robinson to challenge the Canadian constitution and advocate for her right to a legal medically-assisted death (Martin 2016). In September, 1992, Rodriguez, who suffered from amyotrophic lateral sclerosis (ALS), applied to the Supreme Court of British Columbia to have the prohibitions on assisted death struck down, arguing that the criminal code provisions pertaining to assisting suicide were unconstitutional. Although suicide itself was legal after 1972, assisting suicide remained illegal until the *Canada v. Carter* decision in 2015. Consequently, Rodriguez wanted to have her right to have assistance in her suicide recognized. In 1993, the Supreme Court of British Columbia released its decision to uphold the criminal code (Beaudoin 2006), and Sue Rodriguez ultimately pursued a clandestine assisted death.

Through the development of the Rodriguez case and growing public awareness of the issues surrounding MAiD, non-governmental organizations continued to advocate for MAiD, provide resources and support to those who sought it, and in some cases, carry out clandestine assisted deaths (Martin 2016). Renewed political and legal efforts, however, did not materialize until the early 2000s, first in Quebec, and then in the English-speaking Canada. From 1992 to 1994, following the Nancy B case<sup>12</sup>, the right to refuse treatment was legalized in Quebec, and became recognized in the province's civil code (Martin 2016). In 2009, Parti Québécois MNA Véronique Hivon successfully motioned, in the Quebec national assembly, to establish a task

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<sup>11</sup> According to Sandra Martin, Hofsess and Rodriguez parted ways before the Supreme Court decision, after Hofsess published an article claiming that Rodriguez planned to die publicly Martin, Sandra. 2016. *A Good Death: Making the Most of Our Final Choices*. Toronto: Harper Collins..

<sup>12</sup> Nancy B was a Quebecois woman who suffered from Guillain-Barré syndrome, a degenerative condition that left her dependent on a ventilator to breathe, and in effect bound to her hospital bed. In 1991, Nancy challenged the Hôtel Dieu de Québec (a hospital in Quebec City) and asserted her right to refuse treatment. The case was taken to the Quebec Superior Court, which ultimately, in 1992, upheld Nancy B's right (See Dickens, Bernard. 1993. "Medically Assisted Death: Nancy B. v. Hôtel Dieu de Québec. *McGill Law Journal* 38(3): 1053-1070.)

force to study MAiD and other end of life issues. Following the tabling of the task force's report in 2013, the Quebec bill on assisted death, Bill 52, was passed in 2014. In effect, MAiD was legal in Quebec before it was legal in the rest of Canada.

Shortly following the passage of Bill 52, the Carter case was brought to the British Columbia Supreme Court. As Sandra Martin points out, by the second decade of the 2000s, the right to die movement, in addition to being buoyed by Bill 52, was much more established than it had been at the time of the Rodriguez case: "In 1992, Rodriguez was represented by a single overworked lawyer, the Right-to-Die Society was run out of somebody's house, the evidentiary record was negligible, and the entire case rested on one plaintiff, Sue Rodriguez, whose health was rapidly disintegrating." (Martin 2016). The Carter case, however, was spearheaded by the BC Civil Liberties Association and the now expanded Dying with Dignity, both of which had the resources to see the case to its conclusion. In its final form, the lawsuit included: the BC Civil Liberties Association; Lee Carter, who helped her mother Kay Carter to travel to Switzerland for assisted death through Dignitas<sup>13</sup>; Lee's husband, Hollis Johnson; a palliative care practitioner named William Shoichet; and Gloria Taylor, who was suffering from ALS (Martin 2016). The suit was ultimately successful, with the Supreme Court of Canada striking down the criminal code provisions on assisted suicide in 2015. By 2016, the Trudeau government had passed Bill C-14, which established a federal MAiD policy in Canada.

### *Current MAiD Policy*

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<sup>13</sup> Dignitas is a Swiss organization that helps people die. To access Dignitas' services, a person must first become a member of the organization, and then undergo a rigorous assessment process. Under Swiss law, suicide is legal, but directly assisted death by administering a substance is prohibited. At the Dignitas facility, patients are given lethal drugs, which they then self administer, either intravenously, or orally. (See <http://www.dignitas.ch/?lang=en> for more information)

In terms of policy, in Canada, the legislation governing MAiD is split between the federal government and the provinces. Bill C-14 is the cornerstone legislation for MAiD, while the individual provinces have their own Bills (for example, Bill 84 in Ontario (see Hoskins 2017) and Bill 52 in Quebec), guidelines crafted by the provincial colleges of physicians and surgeons, or both. Consequently, the Canadian MAiD system is relatively consistent from one province to another, with minor differences in the approval and assessment process. Eligibility criteria are enshrined in Bill C-14 and thus federally. In respect to procedures, euthanasia (voluntary or non-voluntary) remains prohibited; physicians or nurse-practitioners cannot legally administer the MAiD procedure to a patient who is incompetent to reiterate their consent on the day of the procedure, even if there is a clear advance directive.<sup>14</sup> There are two ways that MAiD is carried out currently; a health practitioner can directly administer the drug<sup>15</sup> to cause death, or he, she or they can prescribe the drug, which is then self-administered by the patient. Physicians and nurse practitioners can provide MAiD, while pharmacists, family members or friends, or helping professions in healthcare can assist.

Anyone wishing to receive the MAiD procedure in Canada, must go through a rigorous process of assessment and consent. To be eligible for MAiD, a person must meet the following requirements (2018a):

1. Be eligible for health services funded by the federal government
2. Be at least 18 years old and mentally competent

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<sup>14</sup> The requirement that people be competent up until death has been a source of concern for the MAiD movement, since it effectively bars dementia sufferers from accessing the procedure. For this reason, as will be discussed in later pages, the Canadian MAiD policy includes a stipulation to waive the ten-day waiting period for the procedure, so that consenting patients do not lose competence (and therefore the ability to consent) while waiting for the procedure.

<sup>15</sup> By allowing physicians or nurse practitioners to directly administer drugs, the Canadian government has made the procedure accessible to patients suffering from conditions that hinder their capacity to self-administer oral drugs or compromise their ability to press a button or plunger connected to an IV. In comparison, Switzerland, which for years was the main destination for people seeking MAiD, only the self-administration of lethal drugs is legal.

3. Have a grievous and irremediable medical condition
4. Make a voluntary request for medical assistance in dying that is not the result of outside pressure or influence

Bill C-14 sets out a three-step process through which eligible Canadians (the option is only available to Canadian citizens and permanent residents) can access MAiD. The process begins with the request for MAiD, and ends with the person's death. The first step is that a patient makes a written request for MAiD, witnessed by two independent witnesses – people who are neither the patient's attending physician(s), immediate family members, or otherwise beneficiaries of the patient's will – and submitted to the attending physician. If the physician or health care practitioner exercises the right of conscientious objection<sup>16</sup>, he or she must immediately refer the patient to a physician who is willing to continue the process. Next, if the physician does not object on conscientious grounds, the process continues, with two independent assessors, both of whom are either physicians or nurse practitioners. The assessors meet with the patient, hear the request, and review the case to determine if the patient meets the eligibility criteria for MAiD in Canada. Third, the patient must wait ten days<sup>17</sup>, from signing the written MAiD request, before receiving the MAiD procedure. The patient must also grant consent immediately before MAiD is provided, and can withdraw consent at any time. From December 10<sup>th</sup>, 2015, to December 21<sup>st</sup>, 2017, 3714 people received MAiD (Health 2018). According to the

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<sup>16</sup> Under the Canadian Charter of Rights and Freedoms, individuals have a right to object to actions if they conflict with personal religious convictions. In Ontario, the College of Physicians and Surgeons adopted a policy “mandating effective referrals” for euthanasia. The Christian Legal Fellowship, The Evangelical Fellowship of Canada, and the Assembly of Catholic Bishops of Ontario, along with the Christian Medical and Dental Society of Canada, challenged this policy in the Ontario Supreme Court. The Supreme Court upheld the College's policy (See [http://www.dyingwithdignity.ca/cpso\\_decision](http://www.dyingwithdignity.ca/cpso_decision) and <http://www.christianlegalfellowship.org/projects/> for more information). This means that while conscientious objection is possible, physicians in Ontario are required professionally to refer patients that request MAiD.

<sup>17</sup> The ten day waiting period can be shortened, if the assessors deem that the patient is likely to lose the ability to grant consent before the waiting period elapses.

last two interim reports (Health 2017, Health 2018), the majority of these deaths were accessed due to cancer-related illnesses, and are split relatively evenly between home and hospital.

### *Conclusion*

The legalization of MAiD represents an important social change in Canadian, and perhaps global, society. In the first place, it represents the general acceptance – despite some resistance – of the legitimacy of actively ending lives in the context of prolonged dying. Secondly, at the global scale, it amounts to another jurisdiction joining the list of those where MAiD is legal, revealing the increasing legality of the practice worldwide. There are many social forces leading to the legalization of MAiD; in this chapter I discussed the most direct factors that can be linked to the rise of the MAiD movement, and which set the general context for the development of belief in autonomy, and its centrality to the pro-MAiD identity. The decriminalization of suicide, the problematization of death through the hospice, palliative care and patient rights movements, as well as the legal cases, particularly the Sue Rodriguez case, all contributed to the opening of the debate around death. In the next chapter, I discuss the methodology of the dissertation and the development of a strategy for analysing the pro-MAiD identity.



### 3: USING GROUNDED THEORY METHOD TO STUDY MEDICAL ASSISTANCE IN DYING

In this chapter, I discuss the methodological rationale of the study, including the research goals, the research design, and the specific procedures I used to conceptualize, gather, and analyze the data. The purpose of the study was twofold. In the first place, I set out to gain a greater understanding of the forces driving the increase in support for physician-assisted death – forces that culminated, in 2016, in the passage of Bill C-14. Secondly, I conducted the study to develop a theory of how people develop moral identities. As the study progressed, emphasis shifted from a general theory of morality to how social actors involved in the right to die movement constructed euthanasia as a moral good.

According to critical realism, individuals face a reality that contains cultural principles and structural forces, two things that they reflexively negotiate to formulate life projects and plans for action. Consequently, the goal of the study was to understand 1) the specific cultural and social forces that actors account for while formulating a morality around medical aid in dying and 2) the social psychological process through which this occurs.

#### *Evolution of the Research Design and Questions*

The realist assumption that human actors are reflexive – that they take themselves as objects in their cognitive processes – is at the heart of this project. The utility of this theoretical assumption is that it is anti-reductionist. It frames humans as multi-dimensional actors, with concerns in multiple domains of life, from the “natural” to the practical, to the social. This is important not only for the theoretical reasons described in previous chapters, but also for methodological ones. An anti-reductionist theoretical frame accommodates the diversity of

concerns that motivate human action, as well as provides tools for analysing those concerns in a theoretically rigorous way without stifling the emergence of findings from the field.

This combination of proceeding from a realist theoretical frame, but remaining open to new insights from data, informed the design of the dissertation research. The theoretical frame discussed in Chapter 4 specifies important concepts such as social structure, social action, morality and other central ontological concepts. Critical realism involves a “dual” conception of social life, seeing social structures, cultures and individuals as having their own causal properties. In practice, this means there are multiple analytical levels upon which one can focus. There is structural morphogenesis, or the emergence of structural properties over time. There is cultural morphogenesis, or the emergence of cultural properties over time. Finally, there is personal morphogenesis, or the emergence of personal identities over time.

In this project, the focus was on personal causal powers, specifically, the concerns that people articulate as part of their “pro-euthanasia” identities. The strategy here was inductive, as the goal was to start with concerns as they present themselves to individual actors, and “work up” from these concerns to an understanding of what is occurring at the macro-level. This might appear to make the project methodologically individualist; but, critical realism, with its dualist conception of society, precludes simplistic explanations (such would be upward conflation) of how individual concerns lead to aggregate level changes, as the actions and motivations of individual actors are tempered by political struggles that occur between primary and secondary agents, as well as between agents of different social groups. Simply put, the project is more concerned with explaining how social factors impact individual reflexivity, than explaining how that reflexivity has been shaping the political struggles around end of life. Nevertheless, by explaining one half of

the situation – personal morphogenesis – the project is an opening into a deeper understanding of the moral changes happening at the societal level.

Although the project began with a theoretical frame, its design was emergent.<sup>18</sup> The goal was to use the set of concepts provided by the theoretical frame, as well as by the extant literature, to generate a workable preliminary research question, which would open, rather than shut, empirical investigation. The role of literature in grounded theory is disputed (Charmaz 2006:165). Some grounded theorists have advocated for a minimalistic use of literature in the early stages of research projects (Strauss and Corbin 1990:49-50), with this procedure taking its most extreme form in Glaser’s classic “dictum” that “there is a need not to review any of the literature in the substantive area under study.” (Glaser 1992:31). The primary concern for grounded theorists is that reading too much of the existing literature will cause the researcher to prematurely adopt theoretical categories to analyze the data. Such categories might not fit the data very well and will hinder the task of developing new theory (Charmaz 2006:165). Nevertheless, grounded theorists acknowledge that researchers will have a knowledge of the literature in their area, and that for graduate students and other scholars writing in a relatively rigid format – the dissertation or grant proposal – having a literature review at the beginning of the project is typically required (Charmaz 2006, El Hussein, Kennedy and Oliver 2017:1200).

Following El Hussein and others’ argument that the use of the literature review should be “dynamic, reflexive and integrative” (El Hussein, Kennedy and Oliver 2017) as well as Charmaz’s suggestion that the literature review should be used to provide context for grounded theory (Charmaz 2006), I followed an iterative process for literature review, in which the preliminary

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<sup>18</sup> Having an emergent design meant that the orienting research questions evolved throughout the research. In particular, the use of grounded theory meant that analysis produced new research questions that directed theoretical sampling. For a list of research questions, see Appendix C.

review set the context for the initial research question and subsequent research. In the preliminary literature review, I outlined structural and cultural factors which previous scholars had identified as potentially explaining the increase in pro-euthanasia sentiment:

- 1) gender, race and class
- 2) secularization and autonomy

None of the existing findings on gender, race and class were definitive. While the results of the studies in which secularization and autonomy were hypothesized to be significant explanatory factors were more robust, the literature on these factors lacked a social psychological theory of how secularization and autonomy were experienced by individuals. In this regard, the initial research question was integrated into the existing literature, since it addressed a gap where new theory could explain the social processes producing statistically significant relationships.

The goal of the project then was to use a qualitative method to develop more robust theoretical accounts of how previously identified, as well as previously unforeseen, social forces motivated individuals to become pro-euthanasia. I then returned to the literature after my own grounded theory emerged, using that literature to situate and contextualize my theory. The idea was that if people are reflexive actors, macro-level processes like secularization and the emergence of the cultural principle of autonomy could only influence euthanasia morality if they entered into the life projects of specific actors implicated in the political struggle over end of life. Ironically, the focus then became death – the death of oneself and death of others – as a kind of life project. What were the concerns that shaped support for MAiD for specific actors? While there is a sizeable literature on the concerns medical professionals have about end of life, there is limited literature on laypersons' experience of social and cultural forces, and reconstruct their personal moralities about death in response to those forces.

### *Qualitative Design*

Based on an initial literature review, it appeared to me that the sociological research on euthanasia attitudes was primarily a quantitative endeavour, with a few qualitative studies. Aside from the study by Baeke et al (2011), the majority of the research done on structural and cultural factors has been quantitative. What was missing in the literature was qualitative work that explained how principles such as autonomy, as well as structural factors like gender, are “put into play” at the microlevel. While the quantitative work verified or falsified specific theoretical claims about relationships between deductively-derived explanatory variables and euthanasia attitudes, there was little attention to the process through which these variables lead to action. The question of *why* something like the principle of autonomy becomes a motivating force for people, or how it is negotiated by social actors in specific contexts, was unanswered.

To respond to this gap, I framed the research questions in terms of process. This framing also made qualitative methods the best choice for the project. In the first place, by using a qualitative approach, I would be able to generate new theories about the change in people’s views towards end of life. This would allow me both to identify new variables or processes that had previously been untheorized in existing literature, as well identify in more detail the process through which previously identified variables – such as an increase in beliefs about personal autonomy – were taken up and put into practice by reflexive actors. Second, a qualitative design would provide data about how individuals experience social forces, and act in the context of those forces. Ultimately, I chose grounded theory for this project.

### *Using Grounded Theory Method to Study Medical Assistance in Dying*

Grounded Theory Method (GTM) or sometimes just Grounded Theory, refers to a type of research design where the goal is to generate theory from data. The design is relatively flexible,

depending on the variant, with Charmaz describing it as “systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves. The guidelines offer a set of general principles and heuristic devices rather than formulaic rules.” (2006:2) Charmaz’s cast of GTM as a set of heuristic devices contrasts with Strauss and Corbin’s definition of GTM as “a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon.”(Strauss and Corbin 1990:24). The first central idea to note about GTM is that it is a method for producing a grounded theory. That is, the product of GTM research is “a theoretical formulation of the reality under investigation” (Strauss and Corbin 1990:24).

The expression “grounded theory,” suggests two questions: first, what does it mean to be grounded, and second, what is theory? In the tradition of GTM, the concept of “grounded” or groundedness refers to the relationship between the development of theory and empirical data. In Corbin and Strauss’ classic formulation, “data collection, analysis, and theory stand in reciprocal relationship with one another.” (Strauss and Corbin 1990:23). Although the research design of GTM can be considered inductive in the general sense, in that one moves from empirical data to produce a theory, the specific process of going from the data to the theory has been called “abductive.” “[Abduction] consists of assembling or discovering, on the basis of an interpretation of collected data, such combinations of features for which there is no appropriate explanation or rule in the store of knowledge that already exists. (...) *Abduction* ‘proceeds,’ therefore, from a known quantity (=result) to *two* unknowns (=rule and case).” (Reichertz 2007:219-20). Abduction

then refers to the relationship between developing a theory (a “rule”) and the simultaneously delineation of a case to which that theory can be fit.<sup>19</sup>

Abduction becomes useful in situations where neither the empirical bounds of the case are clear, nor is there a theory readily available to explain it. What counts as a “case” in a macro-level, societal shift? The legalization of MAiD, as conceptualized here, is the historical result of distinct processes, ranging from the political process surrounding the tabling, debate and passage of Bill C-14, to the legal process surrounding the court cases related to MAiD, to the social process through which individuals identify as pro-MAiD. If one were to take an inductive approach, one would have to delimit the case *a priori* and run the risk of missing connections between the structural level, the socio-cultural level, and the person level. Similarly, relying on deduction in the case of MAiD, where there are numerous social correlates, each with different ontological characteristics, and each appropriate to a distinct level of analysis of analysis, would mean reaching for theories that might not yet exist, or ones that exist, but are inappropriate within the critical realist framework. For these reasons, abduction is a much more useful approach. In abduction, one begins with the result, here the narrative of euthanasia as a moral issue, and works from that result to delimit the empirical field that produced the narrative, as well as construct a theory explaining that production. This involves a constant movement or “constant comparison” (Glaser and Strauss 1967) between emerging theoretical concepts and empirical cases within the field of study.

A grounded theory is opposed therefore to theory derived from pure deduction or induction. In the abductive, GTM process, one begins with a lay theoretical narrative (i.e., MAiD is a moral good), and analyzes the data to construct – in conjunction with participants in the field – a secondary narrative of how the first, lay narrative is produced. In this sense, then, grounded theory

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<sup>19</sup> See Appendix B for further information on how the “casing” method in this research compares to the casing method in alternative designs, such as the extended case method.

is “grounded” because it starts with the theoretical narrative supplied by the field, and remains close to that narrative throughout the entire analysis. By using GTM, one avoids incongruencies between pre-conceived theoretical explanations and the case, as well as interpretations produced *a posteriori* by a purely inductive design. Grounded theory is grounded, consequently, because it relies on the data in both for delimiting the case as well as for developing the theory.

The question of whether theory is grounded also goes with the question of theory itself. What is theory? The GTM tradition encompasses four distinct approaches, each which contains a definition of what the goal of theory should be (Apramian et al. 2017:361). The four traditions in GTM are two “schools” created by Glaser and Strauss after their falling out over the best way to conceptualize and do GTM, and approaches developed by Kathy Charmaz and Adele Clarke, respectively. According to Apramian, for Glaser and Strauss, theory is a product, while Charmaz and Clarke emphasize theory as a practice, or “theorizing.” (Apramian et al. 2017:361)

In Glaser’s formulation, theory consists ultimately of explanations of universal social processes that transcend any one substantive domain. The goal of GTM is, correspondingly, to extract from an empirical situation general concepts that will be of value to formal theory, which transcends specific social situations (Apramian et al. 2017:360-61). For Strauss, theory can take multiple levels of abstraction. He acknowledges the utility of formal theory, but also problematizes it with the idea of “complexity” -- that empirical phenomena are typically irreducible to abstract theories. Instead, he suggests that a kind of “analytical description” can be theory. That is, using concepts to describe what is happening in a particular social situation (Apramian et al. 2017:364). In both of these views, the goal of grounded theory is to produce a theory of varying abstraction. While Glaser emphasizes formal theory, Strauss’ approach is more focused on producing an adequately complex explanation of the specific situation.



In Charmaz's version of grounded theory, the emphasis is on "accurately" capturing the voices of her research participants, and telling a story of how their experiences are shaped by social forces. She argues thus for describing the perspectives of the research participants and theorizing the origins of these perspectives in social forces (Apramian et al. 2017:365). Describing the goal of grounded theory, Charmaz writes, "our work culminates in a 'grounded theory,' or an abstract theoretical understanding of the studied experience." (Charmaz 2006:4). While for Glaser, and to some extent, Strauss, the goal of GTM is to produce a formal theory, for Charmaz, GTM is about producing a substantive theory. In this regard, GTM has the potential to contribute new concepts to a specific area of literature (Charmaz 2006:169), concepts which could be borrowed in other areas. However, the emergent theory is not tasked with producing formal theories that transcend substantive areas.

While for Charmaz, GTM is oriented to developing an explanation for a substantive area, Clarke, in post-modern fashion, moves away from explanations of substantive fields to description of the multiple perspectives – real and potential, in those fields. For Clarke, GTM is about embracing the notion of exception and difference that was "silenced" in Charmaz's approach. As Apramian et al describe: "By describing the interpretations of objects, processes, situations and the social commitments that people have to them, social worlds/arena-focused theory production makes the assumption of difference and exception the core principle upon which a theory is built." (2016: 366) In Clarke's view, the task of GTM is to describe what is being said and done in a social field, with the goal of revealing actor positions and concerns. That is, Clarke emphasizes documenting diverse speaking and writing positions in a field, over constructing a unified theoretical narrative of what is occurring in that field.

This dissertation study was most informed by Strauss and Charmaz's version of GTM. Although I was interested in how the concepts from the substantive field of medically assisted dying could inform an analysis of morality in general, the project lacked the scope necessary for moving from a substantive to a formal theory in Glaser's style. Rather, the goals were more modest: to explain, how, specifically, the perspective or narrative of "pro-euthanasia" emerged from its social context. I moved closer to Charmaz's approach to GTM because of the emphasis she places on reconstructing the experiences of research participants. Since, in my study, I was interested in the concerns that motivate people to adopt the pro-euthanasia view, I needed an approach to GTM that emphasized individual reflexivity. Writing about coding using gerunds, for example, Charmaz notes that, "We gain a strong sense of sequence and action with gerunds. The nouns turn these actions into topics. Staying close to the data and, when possible, starting from the words and actions of your respondents, preserves the fluidity of their experience and gives you new ways of looking at it." (Charmaz 2006:49). The goal in Charmaz's approach is to examine the social processes in which respondents are embedded, and to explain this embedding with concepts derived over the course of the study.

The method used in the dissertation study followed Charmaz's, which involves four phases: 1) coding, 2) memo-writing, 3) theoretical sampling, 4) sorting. The four phases above are iterative and not chronological, although analysis typically begins with initial coding and ends with theoretical sorting. The steps apply to any kind of data, from interview transcripts, to field notes, to secondary textual data. The goal of this procedure is to develop theoretical concepts – sometimes called categories – and integrate them into a new theoretical narrative about the empirical situation under study. In the next section, I discuss the method for this project, and address coding, memo-

writing and sorting in the data analysis subsection. Theoretical sampling is addressed in the recruitment subsection.

### *Why Grounded Theory?*

Grounded theory was useful to my project because it provided a set of procedures for generating theory. One criticism of qualitative research in general is that it relies on an “anything goes” mentality (Braun and Clarke 2006:26), lacking clear procedures and criteria for judging the quality of research. This is particularly troubling for novice researchers doing qualitative research, who are faced with the daunting task of analyzing a mass of qualitative data, without having access to well-codified and verified statistical and methodological procedures. GTM addresses this problem, by providing clear guidelines for how to collect, analyze and judge the quality of theory. Instead of the procedure for moving from the data to a theoretical narrative being mystified, GTM systematizes the creativity needed to generate theory. Nevertheless, GTM is also flexible enough to accommodate the emergence of unexpected categories and other research directions.

GTM was also a good fit for this project because it is designed to explain the social shaping of individual experience (Charmaz 1990:1166), which is ultimately the focus of the dissertation research. Since it arose in part out of Symbolic Interactionism, GTM emphasizes the link between meaning and action. That is, it begins with the narratives and experiences of research participants, and moves towards an understanding of the social forces shaping those experiences. In contrast with other qualitative approaches that focus on experience – for example phenomenology (Cresswell 1998:51-55) – the aim of GTM is to explain how a personal experience, or the narrative of that experience, is oriented to the social context in which it occurs. This makes GTM especially suited to studies that aim to explain the emergence of a social phenomenon through the individuals participating in that phenomenon.

Consequently, GTM is often used to understand the multiple and intersecting social processes that surround health and illness. In *Awareness of Dying*, for example, Glaser and Strauss set out to discover the social construction of death, and uncover the various “awareness contexts” through which impending death is managed in critical care wards (Strauss and Glaser 1965). In Charmaz’s *Good Days, Bad Days: The Self in Chronic Illness and Time*, she analyzes how chronic illness changes people’s experience of themselves in everyday life: the focus is on the interaction between illness, the Self and social context (Charmaz 1991:6-7). More recently, a number of studies have followed the GTM tradition of looking at the experience of health and illness, with studies of coping strategies for critical illness recovery (Johansson et al, 2004), hip arthroplasty (Jorgensen,2016) multiple sclerosis (Satinovic, 2017). Other GTM studies have included studies of the experiences of patients’ and caregivers’ experiences around chronic illness (Chiang, 2011), and recovery after involuntary psychiatric care (Schon, 2013). These studies are united in their use of grounded theory to understand the way that experiences around health, illness and mortality are shaped by social context, and the variety of ways that social actors navigate these contexts.

The multitude of studies using GTM to examine experiences of health illness suggests that the method is particularly suited to an understanding of how the social actors involved in a phenomenon understand and act toward that phenomenon. Because it originated partially in Symbolic Interactionism, GTM is focused on the experiences and meanings of social actors at the centre of analysis. For this study, which was primarily about how and why actors negotiate social and cultural forces to become pro-right-to-die, it was imperative that I chose a method that was focused on the intersection of experience, meaning, emotion and social forces. GTM, as attested to by the existing studies that use it, is productive in this regard. For example, Charmaz describes the process of “identity questioning” that occurs when people go through serious chronic illness:

“Identity questioning often results from immersion in illness. (...) Ill people wonder where illness will take them and ask who they can be during their odyssey—for self and for others. (...) Identity questioning can lead to feelings of being horrified and overwhelmed by one’s body. To illustrate, a woman who experienced progressive deterioration said, ‘I couldn’t believe it was me. Is this what I can expect?’ In this case, the person learns that a past self may not be regained.” (Charmaz 1991:102)

### *Recruitment*

Theoretical sampling is one of the aspects of GTM that makes it different from other qualitative designs. Sampling in GTM is based on the emergent theoretical categories rather than the characteristics of the population of interest: “our [sampling] criteria are those of *theoretical purpose and relevance* [emphasis in original] – not of structural circumstance.” (Glaser and Strauss 1967:48). Emphasis on concurrent analysis and data collection means that new theoretical leads can be followed as soon as they arise. Because sampling is at the service of theory generation, rather than verifying empirical leads, strategies can be switched on the fly. This was important for the project: because of the abductive nature of GTM, the case (and thus the participant pool) is not specified at the outset of the study. Such information only became apparent after initial coding of secondary documents, and informal conversations with people in the field. Charmaz notes, about theoretical sampling, that “Textbook authors often treat theoretical sampling as a procedure that researchers conduct through interviews. Theoretical sampling is less an explicit procedure than a strategy that you invoke and fit to your specific study.” (Charmaz 2006:107). In my study, I was able to use the logic of theoretical sampling to gather data from a variety of relevant sources, without having to define this gathering from the outset of the project. For example, during interview recruitment, and sometimes following interviews, participants provided me with

documents that they felt were relevant to my project – ranging from personal correspondences with pro-right-to-die organizations to organization newsletters. The flexible, theoretical sampling strategy allowed me to parse the documents for information relevant to the categories I was developing, thus yielding insights about the categories themselves.

Sampling in GTM starts with a general conception of a problem: initial sampling is thus purposive, rather than theoretical. Consequently, the project began with an initial wave of data collection guided by purposive sampling. After this initial wave of data collection and analysis, all subsequent sampling was theoretical, as suggested by Charmaz, I collected data from and about subjects and groups that revealed information about the theoretical categories emerging in the study (Charmaz 2006:96).<sup>20</sup> Since I was interested in learning about pro-euthanasia, I began by monitoring popular media stories about medically-assisted death, attending local events – for example, a town hall meeting organized by the member of parliament in my riding and an event organized by a prominent national pro-right-to-die organization – and gathering secondary documents about the movement, from records of parliamentary meetings, to Supreme Court rulings to written testimonials by people who wanted to access medically-assisted death. I also did two preliminary interviews – one with an acquaintance who was interested in the topic, the other with a pro-right-to-die activist.

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<sup>20</sup> Whereas non-theoretical sampling techniques are guided by the principle of representativeness (that the study sample shares the same characteristics of the population), theoretical sampling is guided by the principle of theoretical saturation. Researchers using GTM gather information on their theoretical categories until no new or relevant information about the categories emerges (Charmaz 2006:96). This is different from the principle of empirical saturation, in which researchers gather data until no new empirical data emerges: “Perhaps the most common error occurs when researchers confuse theoretical sampling with gathering data until they find the same patterns re-occurring. This strategy differs from theoretical sampling because these researchers have not aimed their data-gathering toward explicit development of *theoretical categories* derived from analyses of their studied worlds. Instead, the patterns describe empirical *themes* in their studied worlds.”(Charmaz 2006:102).

I coded the data from this exploratory phase (initial coding – more on this shortly), and developed a few focused categories – for example, “being in control” and “relating to family” – that helped me refine my interview guide and focus the subsequent wave of data collection. Next, I recruited approximately 10 participants (8 of whom ended up participating in interviews) who were volunteers, organizers, members or marginal participants (followers on social media but not members, people who were on mailing lists but did not donate, etc.) in pro-right-to-die organizations in British Columbia, Alberta, Saskatchewan and Manitoba. In theoretical terms, these individuals might be thought of as what Max Weber referred to as *trager* or “carriers” (Weber 2011:113). a group of cultural standard-bearers: individuals placing themselves at the forefront of social and cultural change. These individuals who consciously and consistently participate in these organizations represent ideal-typical individuals, for whom the life project of pro-euthanasia and its corresponding narrative is present in its clearest and most revelatory form. It is my belief that by analysing the experiences of these individuals, we get the sharpest picture of how the contemporary experience of medicalized death became a moving force towards a social sea-change in how people manage the end of their lives.

I recruited these participants primarily by contacting the directors of pro-right-to-die organizations, who sent a recruitment message through their organization newsletters, and posted it on their twitter and Facebook pages.

The goal of this phase of sampling was to recruit participants who were pro-right-to-die because of their life experiences around bereavement, serious illness and disability. These participants were sampled to saturate categories relating to how laypeople – rather than experts – experience death, bereavement and disability in a medical setting. Consequently, interviews with these participants were focused on their experiences with bereavement – typically having

witnessed and cared for the death of a spouse, grandparent(s) or parent – their professional experiences (a few were nurses or pharmacists. In the final phase of recruitment, the development of the theoretical category of autonomy and its relationship to humanist and secular directed my recruitment. Consequently, I contacted members of the Ontario Humanist Association and the Canadian Unitarian council, who shared recruitment messages in their networks. Some of the participants in this phase also shared the recruitment message after participating in interviews. The grounded theory developed in this dissertation is based, in total, on interviews with thirteen participants<sup>21</sup>, on two participant observations, and on a heuristic analysis of over sixty secondary documents related to the pro-MAiD movement.<sup>22</sup>

#### *Data Collection, Storage and Transcription*

The study included a number of secondary documents, most of which are in the public domain, and so were available electronically. The majority of the data, however, was obtained through semi-structured, in-depth interviews, which were conducted in person and via telephone. Although I originally intended to do all interviews in person, this method would have unnecessarily limited my sample to people within a reasonable travelling distance of the Greater Toronto Area. I started doing telephone interviews so that I could talk to participants across the country. The interviews were between 1 and 2 hours long.

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<sup>21</sup> Demographic data on the sample was not obtained. Due to the sensitivity nature of the topic, and that many of the interviews were done by telephone, it was not possible to get information on age, gender, race and household income where this information was not revealed by the participant during the interview. Nevertheless, some demographic information, for example gender, became relevant to specific participants and figured prominently in their interviews.

<sup>22</sup> In GTM studies around health and illness, sample size ranges from 11 – 65, with a few studies around 15 and 20.



In the first phase of the interviews, questions were focused on eliciting stories about how bereavement or serious illness shaped participants' views on medically assisted death. My goal was to allow participants to connect to the topic in whichever way was most important for them. For several, who had experienced multiple bereavements, there was a "most important" death, that sparked their interest in the topic. For others, it was a combination of factors – exposure to death in a caring-professional capacity as well as personal loss, or severe mental health conditions as well as personal loss – that were most salient to them. I would typically begin interviews with the question, "Could you tell me a bit about yourself?" This gave me an opportunity to shape later interview questions, and to gauge how the participant approached the topic. During participants' response to this first question, they would usually identify several bereavement experiences, and I would ask them to tell me about the one that they connected most with medically-assisted death (in several cases, participants revealed this information in e-mail or telephone communications before the actual interview). Through the rest of the interview, I let participants tell their stories, and intervened with questions to clarify relevant elements – for example, the conversations they had had with a loved one about the possibility of medically assisted death or other desired care provisions.

All interviews were digitally recorded. The recordings were encrypted, stored digitally in duplicate, and then transcribed. Recordings containing identifying information were transcribed by the researcher. Others were transcribed by a bondable, confidential transcription firm. Other documents were saved digitally and cleaned for analysis.

## Data Analysis

### Coding

To generate the theory, I followed Charmaz's method of GTM. I moved through iterative phases of coding (using CAQDAS)<sup>23</sup>, memo-writing, and theoretical sampling. Charmaz defines coding as "naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data." (2006:43). Coding has two phases: "initial coding" and "focused" or "selective coding." (Charmaz 2006:46). In initial coding, the analyst describes each unit of data with a label, attempting to account for as many theoretical leads as possible. This is fundamentally a process of constructing the preliminary parts of a theory about the empirical world under investigation, since it involves the construction of concepts to describe that world: "(...) we define what we see as significant in the data and describe what we think is happening. Coding consists of this initial, shorthand defining and labelling." (Charmaz 2006:47).

In Charmaz's approach to GTM, she advocates, following Glaser, for coding using gerunds (Charmaz 2006:49). Focusing on action, according to Charmaz, encourages the analyst to remain close to the meanings that social actors place on phenomena. By starting with a phrase like "I couldn't believe it was me," and then asking, what is this person *doing*, Charmaz was able to uncover a social process. In my own data, I used a similar approach in my early coding for the concept of "confronting expertise." One participant, an activist involved with helping patients access medically-assisted dying, described a client of hers:

But there are still some doctors that look at their patients and say, 'oh you can't be suffering intolerably.' There's a woman (...) who has terrible panic attacks, and goes to the emergency department and they give her Paxil and send her home, they're tired of seeing her. But it's terrifying to be unable to breathe. It's absolutely

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<sup>23</sup> Data was coded using Atlas.Ti. Atlas.Ti contains applications for organizing memos, codes, and creating networks between elements, which facilitated the analysis.

terrifying. And she has that, but her pulmonologist has given her certain tests, and gotten certain scores, and he says ‘you can’t be suffering intolerably, because you only score at, you know 13’ or something on this scale.

By asking, “what was this patient doing,” and what was this physician doing,” I constructed the concept “confronting expertise,” which refers to how patients and medical professionals negotiate objective medical knowledge. For the patient, expertise is a restriction on her ability to manage her own death. It becomes possible, using this concept, to link up the patient’s and physicians’ frustration with the cultural principle of “doctor knows best.” This short anecdote then reveals multiple social processes.

In this regard, the difference between GTM and some other forms of qualitative analysis, for example, thematic analysis (Braun and Clarke 2006), is that the social process is not simply taken as a statement for what commonly occurs in an empirical situation – the frequency of the idea of questioning identity or confronting expertise is immaterial here. Instead, the empirical fragment is used to build a theoretical narrative about how the *experience* of accessing medically assisted death is impacted by macro-level cultural and social processes like rationalization and professionalization.

In general, coding begins with initial coding and proceeds to focused coding. Initial coding can be done word-by-word, line-by-line, segment-by-segment, or incident-by-incident (for field notes), but Charmaz recommends starting with line-by-line coding for detailed data (2006:50-53). The analysis strategy in GTM relies on the researcher using discretion to decide on how to put the coding strategy into practice, so the decision to code data word-by-word, line-by-line, or segment-by-segment can be made heuristically, to accommodate the data sources that are sampled during theoretical sampling. When coding individual correspondences, which were relatively terse and dense with meaning, word-by-word coding made the most sense, since it helped me unpack

concise communications and prevented me from taking for granted the meaning in the letters. Coding line-by-line and sentence by sentence made more sense for the interview data, since respondents tend to use more words to complete a thought (they trail off, they repeat words, and so forth). I used segment-by-segment coding while analyzing committee meetings, since the meaning of a particular speaker's utterance often only made sense when taken as a group of multiple sentences. This flexibility helped me focus on the emerging theory, and helped me avoid a scenario where I would have to ignore theoretically-relevant data to conform to a rigid sampling or coding procedure.

During coding, I used "constant comparison" to begin developing central theoretical categories. "Comparing data with data" helps the analyst identify and develop the categories (Charmaz 2006:54). By comparing units of data that have been assigned the same code, the analyst begins to identify the more abstract theoretical category linking the two units of data. For example, consider two interview excerpts:

Excerpt 1

I would go to the nursing home and feed my grandmother lunch and then lift her on and off the toilet. I used to get stares. I can remember some of the staff looking at me, well you don't need to do that. And to this day, I have to tell you, as a nurse, it drives me crazy when families come and visit and sit at the bedside and do nothing, and then look at me and say my mother's fingernails need cutting.

Excerpt 2

This woman had stomach cancer. I've been a nurse long enough to know how absolutely wrong that was, and how cruel that was, and how much pain it would have caused her.

When I walked into the hospital room, she was, at that point, throwing up dried blood, and was extremely dehydrated and ill. I have to say, I just about lost my mind. They got a hold of the doctor, and he wouldn't talk to me, but I'd already told him which orders I wanted for her.

While reading the first excerpt, I asked myself what the participant was doing in the recounted anecdote. Noting that she said "...as a nurse...", I reasoned that her nurse identity was being expressed during this anecdote. Thus, the actions recounted were understood within this frame. Working from a knowledge of the medical sociology literature, as well as my own experiences of bereavement, I assigned the code *doing care work* to the first excerpt. While coding excerpt 2, which was from an interview with a different participant, I noticed the similar turn of phrase "I've been a nurse long enough to know...". Again, the participant was expressing an occupational identity, and using it to make a claim to expertise about care. The frame within which she understood the events of her mother's death, was, as she recounted it, one heavily shaped by experiences and knowledge as a care worker.

This idea recurred in other interviews, sometimes with participants who were care workers, and others who were not. Codes that reoccur frequently, and seem to be theoretically important – that is, being amenable to further abstraction – are designated as "focused codes," or representations of the central concepts of the emerging theory (Charmaz 2006:60). The development of focused codes leads to "focused coding." In this phase, the researcher re-labels data using the focused codes. By using focused codes, the researcher develops the attributes of key categories. By comparing multiple incidents that are labelled under the same major category, the researcher can begin to ask questions about why and how the category differs in the two empirical instances.

Thus, in one iteration of focused coding, I searched for instances of "doing care work" in an interview with a person who was not a health care worker. Consider the following excerpt:

But I saw him [the participant's grandfather] slowly deteriorate where at first he came over and he could walk around. And then at first, he could go downstairs and he would shower, but he was slow, you know? He would cook a little. And he just slowly deteriorated. And he, well, he lived in the living room, so he would watch TV all the time. And then eventually it got to the point where he had to urinate in one of those like jugs and we couldn't really take care of him to that extent.

This excerpt was initially coded as “confronting decline.” In the focused coding, however, I realized that the participant was also talking about caring for his grandfather – in the dual sense of feeling affection towards him (evident in the anecdote about his grandfather's strength presented in earlier chapters), as well as sitting with his grandfather, monitoring him and potentially offering some kind of company or even physical care. However, the way this anecdote was told differed markedly from the participants who identified as nurses as did paid care work. Why? There are at least two answers. First, it could be that this participant might have been significantly younger than the other participants when he was caring for a dying person, and thus was not in a position to provide more intensive care. Another answer is that this participant, who is a man, was not expected to provide more intensive care for his grandfather, and so his care work was limited to listening, monitoring, and potentially helping his grandfather move around. This was one of the pieces of evidence supporting the theory that gender was one factor impacting how participation in care work shaped the participant's view of medically-assisted death.

### *Coding and reflexivity*

Following the above coding procedure helped me be more reflexive, and ensured that I remained close to the information in front of me. Although GTM is flexible – it is sometimes presented as a set of guidelines, rather than rules to follow – careful attention to coding procedure encourages reflexivity about the data. Charmaz writes that “careful coding (...) helps you to refrain from imputing your motives, fears, or unresolved personal issues to your respondents and to your

collected data.” (Charmaz 2006:54). By breaking down the data line-by-line or even sentence-by-sentence, I was able to uncover participant meanings that I otherwise would have missed, glossed over, or interpreted according to my own biases. For example, in an early interview, one of the participants discussed how her elderly father was mortified by the thought of having to wear diapers, because he would feel humiliated by it. In my follow-up question, I asked, “what do you think would be most troubling about this whole scenario of dependence?” After line-by-line coding, I realized that the participant had never actually mentioned dependence – this is something that I imputed onto the participant, due to my own personal reservations. The participant confirmed that her father’s fears were indeed about being dependent, and this gave her an opportunity to discuss how his gender impacted his views on healthcare. While it is impossible to know whether the participant ultimately discussed dependence because I mentioned it first, line-by-line coding alerted me to my own gendered assumptions about care, and prevented me from making the same assumption in later interviews.

Following a systematic coding procedure helped me avoid prematurely focusing on issues or concepts solely because they were part of my personal experience. By adopting GTM procedures around data collection, sampling, and data analysis, I was able to incorporate my personal concerns and preoccupations productively into the project. I mentioned early in the chapter that when the initial project started, I intended to develop a theory of morality, thinking that euthanasia was in itself a moral concern. Adopting the coding procedures and methodological strategies of GTM helped me incorporate my own view of euthanasia as a moral issue by rendering my point of view as something that emerged from the social field. In this way, I was able to take up the moral narrative about medically assisted death as a research object in its own right, something that would not have been possible had I not adopted GTM.

### *Memo-writing*

Memo-writing is a way for the researcher to record important thoughts about categories during the coding process. Memos can be used to develop the definition of a category, describe its scope, and fit it into the emerging theoretical narrative (Charmaz 2006:75-79). Charmaz notes that there is no set method for writing memos: the goal is to get thoughts about the categories written down, so they can serve as a springboard to developing the features of categories and linking categories with other categories (Charmaz 2006:80). For example, in a brief memo on “doing care work,” I recorded the following:

Properties of doing care work:

Degree of remuneration: paid or unpaid

Type of care work: emotional support, physical care, logistical support, etc.

Some types of care are discussed as encompassing these different facets. Ex. palliative care, long term care, could include emotional and physical care. Although these official types (palliative vs. curative) seem to be more a product of the professional point of view than how participants see their worlds.

emotional support: subtypes

physical care: subtypes

logistical support: subtypes

Target of care: strangers, friends, family

Duration: Short or long

Intensity: very involved -- not very involved

Frequency: occasionally -- frequently

Location: Home, outside of the home

Although many of the aspects of this memo never made it into the final theoretical analysis, the memo was useful in beginning to see the dimensions or properties of the concept, alerting me to the possibilities care work appearing in expected ways, such as in the less-intensive care work offered by participant to his grandfather, in the excerpt on the previous page.

Memos are also an important step between codes and categories. While codes are concepts, they describe specific empirical units; categories, on the other hand, are theoretical, in



that they subsume multiple empirical units into a single sociological concept. In memos on focused codes, the analyst drafts theoretical accounts of focused codes, and assesses their suitability as central theoretical concepts (Charmaz 2006:91-92). As discussed in chapters eight and nine, losing identity became a central category of the study. However, it began as a code referring to the process through which people's selves change over the course of a decline in their health. In a memo on the code "losing the self/losing identity" I wrote the following:

### Losing the self

Loss of self means being involuntarily dispossessed of former attributes and sentiments that comprise one's self-concept, as well as the actions and experiences upon which they are based. It also means losing the self-definitions with which one had most identified. With loss of self, earlier boundaries of the self shrink and become permeable. The self grows vulnerable to the demeaning images reflected by others. The attrition of former attributes and sentiments results in changed feelings about self. Resignation follows. Hence, loss of self results in passivity." (257).

One aspect of losing the self is losing the physical capacities of the self. In a blog post, legal scholar Norman Cantor, who is in favour of giving moral and legal weight to advanced directives, notes that the "original specter" in the 1980s was to either have a prolonged death (due to the increased use of medical technology), or being kept alive in a "vegetative" (i.e. unconscious state).

Within this account there are at least two dimensions of losing the physical self. In the first place, there is the idea of being "stuck" or "slowed" down in the dying process. Cantor describes the fear of "burdensome" interventions -- where burdensome here presumably means uncomfortable and pain-inducing. \*\*We can also think again here of a participant's description of the dying person turning inward with suffering. By being stuck in the physical aspects of dying, the basic separation between body and environment that is also necessary for a sense of self, disappears. The dying person becomes entirely preoccupied with their physical suffering -- the dying body becomes their whole world. This is, in a way, an inverted return to narcissism, since the whole world of the patient is sucked into the dying body, instead of the living, infantile body being projected onto the entire world. By becoming preoccupied with physical suffering around dying -- respirators, feeding tubes, IVs, pain, pain relief, immobilization, and so forth -- the ceases to be an action-oriented body, Without this basic pre-condition, it is difficult for the patient to maintain a social self, an emotional self, and others selves that might in fact be desirable over the course of death.

This memo allowed me to develop some of the theoretical dimensions of losing the self, which by then had become a focused category. Memos written in this way also were a vital link between the emerging theory and the existing literature.

### *Theoretical sorting, diagramming and integrating*

Sorting memos helps the researcher connect the ideas in different memos into a provisional theory (Charmaz 2006:115). There is no set procedure for how to connect memos, but the goal is to create a first version of the theoretical story. The researcher uses a heuristic process to compare categories, establish links and decide on the process that the theoretical narrative is describing. One strategy Charmaz recommends is printing out memos of the major categories, and arranging them physically into an order that seems to capture the process in the data. This order can then be diagrammed (Charmaz 2006:117-18). Although I did not print out the memos, I used mind maps within Atlas.TI to connect memos and categories. The written memos themselves were aids to the integration of the categories within the existing literature.

### *Evaluating Research Quality*

Like other qualitative methods, GTM includes criteria for evaluating research quality. Since GTM is about generating theory, the criteria relate to the quality of the theory produced in a particular research study. While Glaser and Strauss include quality criteria in the earliest statement of GTM, Charmaz has developed criteria tailored to her approach. Charmaz's criteria incorporate and go beyond Glaser and Strauss' original criteria. Charmaz recommends the following four criteria: 1) credibility, 2) originality, 3) resonance and 4) usefulness (Charmaz 2006:182-84). I strove to incorporate these criteria into my research design.

Credibility, which Charmaz borrows from Lincoln and Guba (Lincoln and Guba 1985:297), refers to whether the theory can be reasonably said to be based on a grounded analysis of the data, rather than deduction or speculation. Charmaz offers several questions that can be asked to assess credibility, but two in particular encompass the spirit of the criterion: “are the data sufficient to merit claims,” and have there been systematic comparisons between observations and between categories? (Charmaz 2006:182). Procedures for producing credible research are built into GTM, through theoretical sampling and constant comparison. By sampling theoretically, the researcher tries to get as much information as possible about a category, to ensure that the category is a reasonable interpretation of the empirical situation. By comparing data to data and sorting memos to connect categories, the researcher develops the properties of categories. These two procedures produce theoretical concepts with depth and breadth.

Originality refers to the theoretical and social significance of the theory (Charmaz 2006:182). Establishing the significance of a grounded theory relies on positioning the work within scholarly debates. This is one of the reasons that Charmaz recommends close familiarity with literature at the planning stage of the project, and then a sojourn from it while writing the grounded theory: “The proposal demanded a sophisticated knowledge of leading studies and theories in your field. If so, you can let this material lie fallow until after you have developed your categories and the analytic relationships between them. Then, begin locating your work in the relevant literatures.” (Charmaz 2006:166). Following a delayed literature review process, like the one I adopted in my study, encourages the researcher take some critical distance from existing theories and concepts. This hiatus gives the space necessary for the development of original thought (Charmaz 2006:165). Then, having developed a ground theory, the researcher can re-engage the literature by weaving discussions of extant concepts throughout the grounded theory – in its

developed form. By doing so, the researcher demonstrates the contributions that the theory makes to scholarly debates.

Resonance refers to whether the grounded theory is relatable to the participants in the study, and whether it reveals new insights about their lives (Charmaz 2006:182-83). As Charmaz notes, a credible theory – one based closely on the data – is more likely to resonate with people in the field (Charmaz 2006:183). Theoretical sampling and flexible data collection also bolster this resonance. Since data analysis and collection proceed in alternating phases, the researcher can conduct member-checks (Lincoln and Guba 1985:314) as data collection unfolds. I used this strategy during my study. For example, after coding an early interview, I developed a tentative theoretical connection: the management of death seemed to be shaped by the connections one has with one's close family and friends while dying (coded as "relating to family"). To check this connection, I asked a subsequent respondent about the relevance of family relations, something which the respondent attested to, and provided anecdotes about. Not only was such member checking vital to theoretical sampling: it also meant that the emerging theory was directly relevant to participants, since it was based on their interpretations of the situation.

The final criteria, which relates to resonance, is that the theory be "useful," (Charmaz 2006:183) both to other scholars and laypeople. In terms of usefulness to scholars, crafting a useful grounded theory requires situating the theory in the literature, as discussed earlier, and demonstrating that the concepts are abstract enough to potentially be applied to other research situations. In terms of making concepts abstract, this follows from properly coding the data. Charmaz notes that codes should neither be too general, nor should they simply summarize the data (Charmaz 2006:69). Codes should be abstract enough that they can be elevated to categories,

and be connected to other research areas. In my study, I strove to code the data at a level of abstraction that enabled me to elevate codes to categories.

Consider the following passage from an interview: “then how do you face the consequences (...) so I mean I have thought about it a lot because I know that my father wants to die if he's in certain situation. I'm not gonna kill him if he's starts wearing diapers but [laughs] but you see what I mean. So how do you face knowing what someone wants and not really being able to do anything about it. And what if you're going to have to do something about it.” I initially coded this segment as “feeling powerless to help father.” This initial code was summary; it did not permit me to make any connections with other incidents. Instead, I recoded it, and coded subsequent related segments of data as “relating to family.” The new code was more abstract, so it allowed me to subsume related incidents into the same concept, as well as think about how managing family relationships connected to managing dying. Managing family relationships could of course be relevant in situations where other ethical decisions have to be made, for example, dealing with marital infidelity, child delinquency, settling estates, and so on.

In terms of making the theory useful to laypeople, this again follows from the entire GTM design. Because the categories are grounded in the interpretations of laypeople, the theory is directly relevant to their situation. Nevertheless, because it is a sociological work, it can reveal insights that laypeople would not discover without sociological theorizing. Member-checking is also useful here, since it helps the researcher gauge whether the emerging theory contributes to the lives of participants, by helping them understand their situation.

### *Conclusion*

In this chapter, how GTM was used in the dissertation project, and the evaluation criteria for the research. The study was ultimately motivated by the desire to render a sociological

interpretation of the narrative and experience of being “pro-euthanasia.” What concerns are relevant to Canadians who cast themselves as in favour of medically-assisted death? In the study, I used GTM within a critical realist theoretical frame to interpret participant concerns, and explain the social forces participants account for while developing their moral identities.

The theoretical frame of the dissertation, which provides important tools to explain how the concern for autonomy arises out of the historical context sketched out in this chapter. That is, while we can identify the broad historical forces that contributed to creating a pro-MAiD normative and legal environment, it is also necessary to explain how concrete social actors navigate that environment, constructing the moral identities that lead them to advocate for, and essentially drive forward, the pro-MAiD movement. Critical realism, especially critical realist social psychology, is a way of analytically linking the constraining and enabling effects of social structures, the socializing tendencies of cultural frameworks, and the life projects of concrete human beings. Essentially, the framework presented in the next chapter is a way of understanding how the private concerns of individuals cause them to be aligned with the rise of the pro-MAiD movement. Let us now turn to that framework.

#### 4: THEORETICAL FRAME: REALIST SOCIAL PSYCHOLOGY

The primary purpose of this dissertation is to explain how the historical forces leading to the legalization of MAiD – primarily the rise of the principle of autonomy in death through the patient-rights, hospice and palliative care movements – are navigated and become influential in the lives and identities of social actors. Consequently, the dissertation requires a robust theoretical frame that specifies the components to be explained, including the nature of social structures, social actors, and the linkages between them.<sup>24</sup> The theoretical frame provides conceptions of social structure, of culture, and most importantly, moral identity. The chapter begins with a consideration of social psychology. Since my study addressed how the experience of bereavement and care shaped medically-assisted death attitudes – organized into what I call a “pro-MAiD” identity – it is squarely within social psychological territory. Next, I turn towards critical realism as a way of synthesizing the concepts of identity and morality, into the idea of a “moral identity.”

##### *On Social Psychology*

In short, “(...) social psychology is the scientific investigation of how people’s thoughts, feelings, and behaviors are influenced by the actual, imagined, or implied presence of others.” (Oxford Bibliographies: Sociology, Social Psychology). One can debate about reflexivity and the

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<sup>24</sup> The distinction Sheldon Stryker makes between a theoretical frame and a theory is useful here; theoretical frames or frameworks provide sets of concepts and epistemological priorities. Theories, by contrast, explain specific social phenomena Stryker, Sheldon K. 2008. "From Mead to a Structural Symbolic Interactionism and Beyond." *The Annual Review of Sociology* 34:15-31.. Consequently, while I develop a grounded theory of pro-MAiD identity, that theory cannot be understood apart from the critical realist social psychology that provides fundamental concepts, as well as the epistemological priorities of the study.

body as potential boundaries between the social and psychological.<sup>25</sup> What they point to, however, is the existence of two separate orders of reality, the link between which needs to be specified.<sup>26</sup> In *Being Human*, Margaret Archer argues that humans are involved in a fundamentally practical way with the world. “Reality”, she writes, “be it natural or artefactual, has properties and powers which do not depend upon knowing subjects” (Archer 2000:160). Human knowledge is initially practical; we learn through a “tentative participation in nature”

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<sup>25</sup> Social psychology itself is a contested concept. According to renowned social psychologist James House, social psychology is in a decades long decline – its “golden age” has come and gone House, James. 2008. "Social Psychology, Social Science, and Economics: Twentieth Century Progress and Problems, Twenty-First Century Prospects." *Social Psychology Quarterly* 71:232-56.. Yet social psychology persists, if marginally so. For some researchers, myself included, the social psychology, as a general orientation to sociology, remains useful. Kenneth Gergen offers an influential, constructionist critique of social psychology. According to Gergen, the creation of social psychology amounted to an “intellectual tour de force”; by analysing the link between psychological and sociological processes, social psychology seemed positioned to unite the rigorous psychological theories of Wilhelm Wundt, William James and Sigmund Freud with the new insights of Emile Durkheim, Gabriel Tarde and other early sociologists Gergen, Kenneth. Ibid. "On the Very Idea of Social Psychology." (4):331-37.. Still, Gergen notes that since these early beginnings psychological and sociological social psychologists have operated under two different theories of causality: though both groups study the relationship between mental and social processes, each assumes a causality fitting within its own object field. Psychologists tend to emphasize the causal efficacy of the individual personality in social relations, while sociologists emphasize the influence of the social process on individual cognition and behaviour *ibid.*.. For Gergen, these different notions of causality stem from a fundamental ontological divide between two incommensurable orders of discourse. *Ibid.* In other words, psychology has no need for sociology, and sociology no need for psychology; adherents of each discipline can easily explain their objects of study without recourse to the concepts of the other discipline – the quality of these explanations notwithstanding.

Accepting Gergen’s critique largely depends on accepting his argument that the “psychological” and the “social” are merely orders of discourse, and refer to nothing real. I, for one, do not accept this argument. Phenomenologically, people tend to relate to the sensation of a distinct inner world. As will be discussed later, Margaret Archer makes a compelling case for the existence of reflexivity. That reflexivity exists as a universal feature of human existence suggests that the psychological has an existence outside of the social. Of course, one could argue, as G.H. Mead does, that this reflexivity is a thoroughly social phenomenon. Even if that point is granted, the human body remains a limit to the social. It is never thoroughly socialized.

<sup>26</sup> Social psychological theories that attempt to explain the social solely on the basis of the psychological neglect the causally efficacious aspects of social structure, such as the allocation of opportunity and constraint in social networks, for example. Similarly, sociological theories that ignore the psychological run the risk of ignoring that people think in the context of a brain and body that are not entirely social, and in a way, make their own demands on the individual.



(Archer 2000:160). The world in which we participate is not a blank slate, waiting to be written over by orders of discourse. Rather, our own bodies are part of natural reality. We learn about them and their relation to the world through practical action, and also learn that they are not entirely under our control. In *Structure, Agency and the Internal Conversation*, Margaret Archer argues that objects can be discovered as “real” if they exert a causal influence on other objects. The object itself need not be directly observable. As will be discussed in a later section, Archer uses this “causal criterion” to argue for the reality of reflexivity. We can use the same criteria to argue for the reality of our bodies, and thus, affective, psychological forces. Even though we cannot point to psychological forces and say “here they are”, such forces have a “subjective reality” (Archer 2003:36).

Once one accepts the reality of the psychological and the social, not merely as orders of discourse, but as causally efficacious objects, it becomes possible to ask how they interact. The project of social psychology is to understand the interplay between the social order and the behaviour and inner life of the individual. Crucially, the focus in social psychological analysis is on the psychological processes through which individuals interact with the social world. Thus, social psychologists are interested in examining a number of processes through which the individual is connected with exterior reality: sensation, perception, cognition and emotion all fall under the purview of social psychology.

In terms of the autonomy principle then, the problem is framed in realist social psychology terms. That is, the dissertation is about explaining how social change – in this case the emergence of a normative principle, its social resonance, and its legal codification – is matched by, and indeed, can only happen through changes at the psychological level. The codification of the autonomy principle in the realm of death relies on a relatively widespread,

normative acceptance of the principle. In turn, this acceptance depends on the capacity of social actors to integrate the idea and norm of autonomy into their biographies and identities in relatively consistent ways as they meet the demands of life and death.

### *Critical Realism*

While this general social psychological orientation is a way of framing the problem, it offers little by way of specific concepts and theories about how the psychological and social intertwine or interact. In fact, the social psychological approach, when taken without further qualification, brings the risk of a naïve epistemological individualism, where social change is explained solely on the basis of what is happening at the level of individual social actors. If one adopts this view, sociology itself loses its uniqueness, since social change can be explained by psychological, rather than sociological facts (Durkheim 1982). The challenge of a truly sociological social psychology is to incorporate the interface between social structures and individual action. What does this mean for the empirical questions about medically assisted death treated in this study? In the first place, it means that one must acknowledge and recognize that the legalization of medically assisted death is the culmination of various aligning social forces, some of them acting at the level of structure, others acting at the level of the individual. Most directly, the legalization of medically assisted death is part of a change to the legal structure of Canadian society. At the same time, it entails changes to the structure of healthcare professions, as well as to the normative structure of society. Secondly, it means that changes at the level of individual people – what they think, feel and believe, are also vital to explaining these larger, structural changes. In other words, the social psychology of morality presented here attempts, however modestly, to partly explain the psychological forces that interact with the structural forces leading to MAiD legalization.

Social psychology must be tempered by a comprehensive social theory that includes the powers of social structures. Critical realism, the frame adopted for this study, provides such a theory.

Realism has become influential in the social sciences (Nash 1999:445), likely because it has been lauded as a way forward through the impasse between constructionism and naturalism (Gorski 2013:659). By definition, critical realism (CR) is positioned against – is “critical” of both naïve naturalism/structuralism ( in the next chapter, structuralism in the guise of practice theory is discussed) which treats social entities as given elements with universal features and determining causal powers, and naïve constructionism (discussed in terms of symbolic interactionism in the next chapter), which neglects the causal powers of social structures in shaping human life, and instead allocates causal power entirely to the level of social interaction. In this sense, CR is a framework that acknowledges both the causal powers of social structures *and* the causal powers of social interaction and individual agency, while avoiding conflating them. That is, the goal in CR is to specify these powers, and their relationship to each other, with the aim of providing a framework to explain empirical social change (morphogenesis) or stagnation (morphostasis). When applied to studying a moral issue like medically assisted dying, CR is useful because it can accommodate the diversity of forces that coalesce to produce a societal moral change. Indeed, one of CR’s biggest strengths is that it provides a robust frame for explaining social change.

The concept of morphogenesis captures the social changes that have occurred around medically assisted death. Morphogenesis is the set of “processes which tend to elaborate or change a system’s given form, structure or state.” (Buckley, quoted in Archer 1995: 75) Introducing the concept of morphogenesis to the analysis of MAiD allows us to see the

legalization of MAiD as the outcome of a complex alignment of structural and psychological changes. While this dissertation is focused on the psychological changes (the commonalities in lived experience that make the pro-MAiD identity situationally viable and desirable), the analysis of such changes, when done with a clear conception of social structure, can serve as the groundwork for an analysis of how psychological changes connect to structural morphogenesis. Consequently, it is necessary to contextualize the social psychological analysis here within a broader conceptual frame that includes accounts of social structure and social change: “The practical analysis of society needs to know not only *what social reality is*, but also *how to begin to explain it*, before addressing the particular problem under investigation.” (Archer 1996:5). Consequently, the following pages are spent describing the underpinning theoretical concepts – *what social reality is* and *how to explain it* – and conceptualizing pro-MAiD moral identity.

#### *Tenets of Critical Realism: Analytic Dualism and Emergence*

Much of Archer’s work is focused on resolving the central sociological question of the relationship between social structure and individual action. Consequently, her theory provides robust conceptions of three different, distinct levels of social reality: the structural-cultural level, the socio-cultural level, and the personal level. These concepts are relevant to the analysis of pro-MAiD morality because they allow us to distinguish between the aspects of the empirical issue that are relevant to the research question, and those that are not. Essentially, within a critical realist framework, the three levels of social reality are: 1) The structural-cultural level, which pertains to the forms of structural and cultural organization that exist independently of individual actors and the processes that pertain to those forms; 2) the socio-cultural level – the processes and relationships between individuals and the groups to which they belong; and 3), processes pertaining to individual psychology, personal biographies and life histories. In terms of pro-

MAiD, the issue can be conceptualized within this framework. Broadly, we could analyse the cultural principles and structural constraints pertaining to medically-assisted death that emerge from social interaction over the course of history; here I am referring to the principles marshalled by social actors to make arguments and develop knowledge about the practice of euthanasia. We could also analyze the concrete conflicts that arise – the social-cultural domain – as social actors vie for dominance and to have their preferred principles recognized as the truth. Finally, we could analyse the personal identities and histories related to death, bereavement and euthanasia, which exist at the personal level.

This dissertation is focused on an analysis of how personal identities and histories interface with the cultural level: that is, how personal meanings of death, dying, and euthanasia emerge in the context of given cultural and socio-cultural conditions – what Archer calls personal morphogenesis. Nevertheless, it is necessary to understand how the three levels are connected, as these connections ultimately lay the groundwork for extending the analysis presented here into future work.

Because Margaret Archer conceptualized all three levels, and demonstrates the purpose of each in practical theory, her ontology can be considered “anti-reductionist.” Her anti-reductionism is based on two concepts which she uses to explain the three levels of social reality and their relationships to one another: analytic dualism and the principles of “emergence.” Analytical dualism, is an epistemology and ontology that assumes structure and culture, being characteristics of human groups, must be taken as analytically distinct from the characteristics of individual human beings: “an explanation of why things social are so and not otherwise depends upon an account of how the properties and powers of ‘people’ causally intertwine with those of ‘parts’” (Archer 1995:15). The basic idea here is that societies have different properties from

human beings; each of these “levels” has different aspects that call for distinct concepts to characterize them (Archer 1995:183-85) (Realist Social Theory, 183-185). Nevertheless, these properties interact to create distinct social configurations as well as new forms of personal identity.

The idea that societies – the largest unit of human aggregation – have different properties from individual human beings leads Archer to argue that social analysis must treat human beings and social aggregates in social analysis as distinct entities. Another way of putting this is to say that the properties of societies qua societies are not derived from individuals, nor are the characteristics of individuals qua individuals derived from the societies of which they are part. This is to say that as a type of entity, societies have characteristics that can only be understood as a function of the things that make them different from individual human beings (historical persistence, complex differentiation, sovereignty, etc.).<sup>27</sup> The same can be said of people, who possess qualities that societies do not, like agency, memory, emotion and biographies. Based on the analytical split between society and individuals, Archer argues for a tri-partite epistemology that includes the three levels of analysis mentioned before: cultural principles/structural constraints, the interplay between people and the groups they inhabit, and individuals and their properties.

Archer’s division between these three levels works well as a means of re-conceptualizing social psychology and applying it to the study of MAiD. Cultural principles and structural

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<sup>27</sup> Archer credits David Lockwood with recognizing that “system integration” – the complementarity or conflict between different parts of societies (for example the mode of production and education systems) – is distinct from social integration, which is the degree to which people are integrated into acting groups in the context of system integration. Roy Bhaskar expands Lockwood’s idea into the notions of “the duality of structure,” and the “duality of praxis,” which refers again to two distinct components of social life Archer, Margaret. 1995. *Realist Social Theory: The Morphogenetic Approach*. Cambridge: Cambridge University Press..

constraints serve as a further specification of sociality, while the idea of the interplay between people and groups is a way of specifying psychology in the context of socialization. The analysis of the MAiD movement, then, must attend to these three elements. For the MAiD movement, it is possible then to distinguish between its structural-cultural (i.e. social) dimensions, the “socialization” elements (the interplay between people and groups) and the social psychological dynamics surrounding them. As will be discussed later in this chapter and beginning in Chapter 5, the principle of autonomy is a cultural principle. Social conditions surrounding MAiD, for example the distribution of power in medical practice – between doctor and patient -- are structural elements. Socialization comes into play around the moral background of autonomy, and the way this background is taken up by pro-MAiD organizations. Finally, the individual level is the way that people develop their moral identities in the context of the other factors.

Since analytical dualism rests upon the assumption that social structures and human beings have unique characteristics, analytical dualistic theories require a specification of what these characteristics are and how they come about. Archer conceptualizes these characteristics as emergent properties, a concept that is vital to critical realism more broadly. Initially taken from the philosophy of science, emergence<sup>28</sup> in generally refers to the property of a whole being “[irreducible] to some function of the behavior of its components.” The idea here is that something new and entirely distinct out of the interactions between component parts. For example, in the philosophy of mind, emergence means that the mind is irreducible to the laws governing its physical constituents (Batterman 2009), like neurons, brain hemispheres and so forth. One can know how neurons fire, how they interface together, and how they grow and die,

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<sup>28</sup> The concept of emergence and emergent properties is contested in social theory. Nevertheless, it is an important part of Archer’s framework. Consequently, I summarize here, but avoid assuming specific emergent properties.

without being able to explain anything about the nature of personal identity. Similarly, one can offer an account of one's stream of consciousness without any reference to neurochemistry. For example, one could look at how the nature of different countries' education systems were historically produced by their different social contexts, as Archer did in her doctoral work (Archer 1971), or how a particular civil habitus or disposition to physical restraint and politeness emerged in early modern Europe, as Elias argued (Elias 1982). The characteristics that arise from these emergent processes are called emergent properties.

### *The Structural-Cultural Level*

Being emergent properties, the characteristics of structure/culture and human beings emerge from an ongoing process of interaction between each other. This ongoing process is the centrepiece of Archer's theory; it takes us from analytical dualism to the tripartite framework of structure-culture, socio-cultural interaction, and personal life.

Critical realists define social structure broadly as "forms of social organization (...), real entities with their own powers, tendencies, and potentials," including, amongst other things, "the division of labour, educational systems, [and] political parties[.]" (Archer 1995:106). To avoid lapsing into naïve functionalism, Archer notes that the emergent properties of society are always and everywhere mediated by human actions (Archer 1995:196). Society only exists insofar as there are human beings to enact it. Nevertheless, there is always a temporal gap between society and people. The structures of today are the results of past social interactions, while the actions of people today shape social structure for future generations (Archer 1995:138). The properties of structures are the "objective limitations upon the situations and settings which agents can encounter" (Archer 1995:195). That is, structural properties are defined insofar as they interface with agency. Structural properties limit and enable action by acting as a set of conditions on the



positions that agents occupy (structural conditioning). While social structures and human agency have distinct properties, structure is always confronted by human agents, who can uphold it, subvert it, reinforce it – transform it. Human agency is also subject to social conditions that structure it (Archer 1995:195-96).

Archer explains these conditions as consequences of “vested interests.” Any given position carries an objective grid of benefits and costs to actions in that position. This means that actions have opportunity costs both in terms of actions, and even in terms of interpretation, as wrongly interpreting a social position has consequences for social actors (Archer 1995:203-13). For example, being a secondary school teacher has a set of conditions; one is required to hold a Bachelor’s degree in education, upkeep union membership and work regular hours during the school year. It is possible for individual teachers to subvert role conditions and refuse to pay union dues, but this comes with its own cost. Similarly, interpreting the refusal of union due payment as a strategically sound option in the first place adds an additional, perhaps steeper, opportunity cost. Furthermore, as different structural conditions – attached to different positions – interact, they have the capacity to produce new sets of conditions on agency. Archer explains how contradiction and complementarity between different social institutions creates tension or cohesion for individual agents:

Where incompatibility maintains at the second-order level, then strains are experienced as practical exigencies by agents whose interests are vested in the impeded institutions and their associated roles. In other words, their situations are moulded in critical respects by operational obstructions which translate into practical problems, frustrating those upon whose day-to-day situations they impinge, and confronting them with a series of exigencies which hinder the achievement or satisfaction of their vested institutional interests. On the contrary, where complementarities prevail, these are transmitted to the relevant action contexts as a series of rewarding experiences. The goals which agents pursue and the tasks they undertake by virtue of their roles can be accomplished in a problem-free manner. (Archer 1995)

These new conditions come with “situational logics,” which are the “best” – the most strategically sound per vested interests – to be pursued by agents occupying those positions (Archer 1995:216).<sup>29</sup>

In Archer’s theory, culture functions analogously to structure. Archer defines culture as “all things capable of being grasped, deciphered, understood or known by someone.” (Archer 1996:104). This set of “intelligibilia” constitutes a system of logical relationships between its elements (Archer 1996:104). In this view, two ideas can be compared based on whether they are contradictory (A and B cannot both be true), complementary (A and B imply each other)(Archer 1996:148-52), or, we should add, entirely independent. Like the structural distribution of resources, these logical relationships place those who hold ideas A or B in different “ideational positions” (Archer 1996:145). For example, consider a case where ideas A and B are contradictory. A group that hold both ideas simultaneously will have to deal with tensions introduced by these contradictions endemic to the culture. Thus, in the same way that structure entailed a series of material costs and benefits for each position, Archer argues that ideas also carry objective costs and benefits to those who hold them. They also, continuing in this vein, carry with them situational logics that represent the “best” way of resolving the tensions or upholding a complementary relationship.

By identifying complementary or contradictory structural conditions, Archer further specifies the when, where and how of social transformation. At any given time, present social interactions are conditioned by past states of society; these present interactions will then

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<sup>29</sup> Note: Archer is quite clear that these are objective, and not subjective, reasons for action. The costs and benefits are attached to social positions, but these costs and benefits can be misunderstood, ignored or otherwise interpreted by individual people. In Archer’s view, people do not automatically embody situational logics (Archer, Margaret. 1995. *Realist Social Theory: The Morphogenetic Approach*. Cambridge: Cambridge University Press.)

constitute new social structures (morphogenesis)<sup>30</sup> or reproduce the old ones (morphostasis) (Archer 1995:82). However, given the existence of contradictory and complementary conditions, we now know that complementary conditions will encourage morphostasis. Endemic to complementary positions is a set of benefits and corresponding situational logics that discourage agents from action that would disrupt the complementarity. Similarly, contradictory positions create tensions that encourage agents to act, either to eradicate tensions or transform the positions. In either case, the complementarity or contradiction between social positions is the motor of social change.

As part of the “cultural environment,” the principle of autonomy is a result of the causal powers of culture and its cultural emergent properties. Belief in autonomy, on the other hand, is a result of the causal powers of individuals, which arises as people navigate socio-cultural situations throughout their lives and use cultural principles to make sense of those experiences. The task of uncovering cultural conditioning is to show how the principle of autonomy (the cultural level) is translated into personal belief (the agential level): why and how does the concept of autonomy shape a person’s belief about euthanasia?

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<sup>30</sup> Archer contrasts the morphogenetic view with “downwards” and “upwards” conflation, two types of social theory that fail to adequately conceptualize emergence. In downwards conflation, social structures are thought to determine individual action, without any qualification *ibid.*. In terms of time, future states of society can only be thought of as direct consequences of the properties endemic to current or past social structures *ibid.*. Downwards conflation is problematic because it cannot explain how actors make decisions in social contexts; in this view, actors “hydraulically” *ibid.* replicate social conditions. Marxist and Functionalist theories are good examples of downwards conflation. In upwards conflation, on the other hand, social structures are always a direct consequence of current interaction. No attention is given to how past social structures shape current social interaction *ibid.*. Symbolic interactionism is exemplary of upwards conflation. Finally, Archer contrasts morphogenesis with central conflation, which ultimately neglects time altogether by repudiating the independence of structural and personal properties *ibid.*.

### *The Socio-cultural Level*

So far we have been discussing the elaboration of social structure and culture over time as it conditions and is subsequently transformed by human action, or what Archer calls structural morphogenesis, which is analysed at the structural level. This structural level can be contrasted with the “socio-structural or socio-cultural level,” the level of analysis pertaining to the ways that individuals participate in groups, and the ways that these groups shape social structure. The socio-cultural level involves the interaction between distinct entities that represent increasingly integrated and self-conscious groups of individuals.

Beginning with agents, Archer describes these as collectives that emerge as structure conditions human action. If structure is a set of conditions on what people can and cannot do, it also produces an array of what Archer calls “life chances.” (Archer 1995:257) In short, agents are groups of people with various life chances based on their position in a hierarchy of necessary conditions defined by social and cultural structure.<sup>31</sup>

Archer goes further and distinguishes between corporate and primary agents – corporate agents being well-defined interest groups, who have the capacity to organize and have a say in the kind of action that can transform structure and culture. Primary agents can neither organize nor articulate their interests, and remain beholden to the decisions of corporate agents (Archer 1995:259-60). The emergence of agential properties happens through the interaction of corporate and primary agents. Corporate agents, acting within the conditions set by social structure, set the

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<sup>31</sup> For example, as far as we can speak of a “working class,” this is an agent of an industrial capitalist social structure, a structure which provides increased opportunity for social mobility, consumption, geographic mobility, specialized education, and so forth for capital-owners and less of these things for wage-labourers.

agenda for primary agents, who themselves act back at the corporate agents and further elaborate the group. The best way to think of agency is as a kind of club – corporate agents are the executive, while primary agents are the members at large, who, despite having no formal say in the club’s direction, constitute the human “environment” towards which the executive’s actions are directed:

Corporate Agency thus shapes the *context* for all actors (usually not in the way any particular agent wants but as the emergent consequence of Corporate interaction). Primary agency inhabits this context, but in responding to it also reconstitutes the *environment* which Corporate Agency seeks to control. The former unleashes a stream of aggregate environmental pressures and problems which affect the attainment of the latter’s promotive interests. (Archer 1995:260)

Actors emerge from agents as the specific “organizational roles” or social identities that individual people can aspire to (Archer 1995:255-56).

One way to extend Archer’s theorization of how structure distributes life chances is to extend it to culture as well. As Bourdieu shows, the allocation cultural capital, effectively symbolic resources imbued with status significance in a given social field, positions social actors in social space (Grillo 2018). Thus, culture, as well as structure, also entails social positioning. Though it might not always entail “life chances,” cultural principles group people into distinct units of for and against, as is evidenced by the vigorous debates around ethical issues like genetically modified organisms and vaccines. This is particularly relevant for MAiD, as we can consider primary agents as the members of the public who would consider themselves pro-MAiD as distinct both from people who consider themselves anti-MAiD (also primary agents, albeit of a different cultural position) and from pro-MAiD corporate agents: the organized, funded and politically self-conscious NGOs that advocate for MAiD.

The realist theory of agency grounds Archer’s model of social change, which can also be used to frame MAiD specifically. Recall that the effects of structure and culture – as the

distribution of resources and the logical relationships between intelligible material, respectively – are conditional: they require subjects to interpret and act on them. Agents are consequently the social subjects that act self-consciously on the structural conditions in which they are located. Putting together this notion of agency with the idea of structural emergence, Archer forwards a three-phase, temporal model of social change (Archer 1995:160):

- 1) Structural conditioning: People are born into various positions, each entailing a distribution of material and other resources, and each carrying with it a conditional matrix of costs and benefits
- 2) Social interaction: Based on situational logics implied by the various structural and cultural positions, Corporate and Primary agents interact, working either to sustain structural conditions or transform them
- 3) Structural elaboration: Structural conditions are transformed or maintained through the actions of Corporate agents, who have acted in response both to situational logics as well as the “social environment” constituted by the actions of primary agents (Archer 1995:260)

In this model, existing social structures and culture condition, but do not determine, the social interaction between various agents. These agents in turn interact act in this conditional context, as well as the context of their own interaction, to reproduce or transform social structure, setting the stage for future social interaction.

One of the assumptions motivating the dissertation is that the legalization of MAiD is the outcome of multiple processes of social change, or structural and cultural morphogenesis more specifically. In the first place, the legalization itself is the outcome of structural morphogenesis, since it amounts to a significant change to Canada’s legal structure, in terms of the autonomy

principle around death being codified. While important, this change is in itself not the main subject of this dissertation. Rather, the focus here is on the cultural morphogenesis that was necessary prior and concomitant to the legalization of MAiD. As discussed in the previous chapter, MAiD legalization was the outcome in part of cultural changes to norms, as well as the development of a pro-MAiD movement. Thus, we can analyse the cultural conditioning (the operation of a humanist moral background of autonomy), social interaction (the experience of life events, and the communication and eventually uptake into corporate agency of the identities developed through those experiences) and cultural elaboration (the taken-for-granted status of the autonomy principle as a justification for MAiD).

### *The Personal Level*

To this point, we have been discussing the relationships between structure and the agents that it constitutes, without looking at the motivations of concrete human actors as part of agents dealing with the conditions of social and cultural structure. Structural and cultural positions contain objective, situational logics that represent the “best” course of action for the interests of a given agent. The relationship between structure and the material, social interests of agents is thus a necessary one. The relationship between situational logics and the actions, thoughts and motivations of concrete human actors, however, are conditional ones. Archer notes this point:

(...) the objective distribution of costs and benefits conditions both interpretation and action. Agents opposing the source of rewarding experiences risk harming their vested interests: agents supporting the source of frustrating experiences invite further impediments. By setting prices and premiums on situation interpretations, the conditional influence forces no one: it operates not as a hydraulic pressure but as a material reason which favours one response over another.” (Archer 1995:209)

Although situational logics condition individual interpretation, it is still up to individual people to determine their role or social identity from the available set within an agency. For example,

working-class labourers can decide, during a strike, whether they want to be scabs or picketers; the choice is theirs to make, even though each course of action will certainly come with various benefits and frustrations.

### *Conclusion*

In this chapter I discussed the central epistemological and ontological principles of critical realism. For realists, social structures have distinct causal properties from individual people. These distinct causal properties, in turn, mean that social and cultures need to be analyzed separately, or at a different level, from the properties and causal powers of individuals (analytical dualism). For this dissertation, the concepts of the structural and cultural level, as well as the socio-cultural level, are important, since they provide the tools to contextualize the actions and experiences of the participants in sociological terms, and to connect the micro level with the meso and the macro.

The dissertation itself is focused in particular on the personal level, as it aims to understand the experiences of individuals and how they interpret and organize these experiences into a coherent and shared MAiD identity. Consequently, the personal level, including the concept of identity, deserve more discussion. In the next chapter, I examine the realist conception of reflexivity, in comparison to two competing accounts, and develop the concept of identity that is central to the dissertation.



## 5: THE CRITICAL REALIST CONCEPTION OF REFLEXIVITY AND THE FORMATION OF PERSONAL IDENTITY

In terms of this dissertation, reflexivity, and in particular, the reflexive construction of identity, is the central connection between the individual and exterior reality. For this reason, in the following section, I discuss critical realism as an alternative to two competing conceptions of reflexivity – the symbolic interactionist perspective derived from the works of G.H. Mead and Herbert Blumer, and the “practice theory” perspective derived from the works of Pierre Bourdieu. I argue that the distinctness of the critical realist approach to social psychology, which I employ and develop in this dissertation, is that it offers a moderate constructionist model of reflexivity that avoids the reductionist tendencies of other popular models of reflexivity, namely symbolic interactionism and practice theories. One of the “critical” aspects of critical realism, in fact, is its distance from the naïve constructionism offered in many interpretations of symbolic interactionism, and the tendency towards structuralism in practice theory.

What distinguishes critical realist social psychology from other kinds of social psychology? While the concern with reflexivity is prominent in critical realism, realists are not alone in theorizing and working with the concept of reflexivity. Yet, critical realism offers a specific conception of reflexivity that differs from interactionist and Bourdieusian versions. Critical realism is at odds with the ambiguous treatment of the “I” in symbolic interactionism, and the resulting conflation of personal and social identity. With respect to Bourdieu’s thought, critical realism, in my view, is the critique of Bourdieu’s tendency to over-socialize reflexivity and locate it in what are known in the literature as vertical and horizontal disjunctures. Again, as it did for symbolic interactionism, the location of reflexivity in games of social fields falls short in explaining how identity is reflexively constructed.

### *Reflexivity and Identity in Symbolic Interactionism*

Symbolic interactionism has a controversial legacy. Sandstrom and Fine have referred to its “sad demise”. Still, as they argue, the end of symbolic interactionism – if there is such an end – is likely due to the adoption of interactionist principles in much of sociological thought; symbolic interactionism becomes “triumphant” just as it disappears (Sandstrom and Fine 2003:1042). Symbolic interactionist thought remains important to contemporary social psychology. Symbolic interactionist thinkers have made fundamental contributions in numerous areas, including but not limited to self and identity, emotions, and social coordination (Sandstrom, Martin and Fine 2003:219-23). Consequently, symbolic interactionism merits treatment as a central theoretical paradigm in sociological social psychology, and a competing paradigm to critical realism.

The source of the concept of reflexivity in symbolic interactionism lies generally in the thought of G.H. Mead and the interpretation of Mead’s work by Mead’s students, Herbert Blumer in particular. To start, for Mead, reflexivity is connected to the psychological process of “self.” Mead defines the Self as “that which can be both subject and object” or in terms of consciousness, the “capacity of being of being an object to itself” (Mead 1934:136-37) or the “reflection of Reason on itself” (Mead 1934:138). Mead suggests that as one thinks, that is, carries on an internal conversation of gesture, the Self is constituted (Mead 1934:152).

Consequently, for Mead, reflexivity is the fundamental mode of human thinking. On this point, critical realism and symbolic interactionism are on the same page. They diverge, however, when one begins to consider the genesis of reflexivity. For Mead, reflexivity is learned in childhood. When children play at different roles in groups, they learn the attitudes that one typically takes towards a particular stimulus (Mead 1934:151). As children get older, play gives

way to games, which are more rigidly organized, and demand that a person be not only able to internalize one role at a time, but rather, to simultaneously understand all of the roles in a group and the proper attitudes one takes when adopting them (Mead 1934:151). This culmination of attitudes, associated with all of the roles in a group, Mead calls the “generalized other” (Mead 1934:155). The Self then, Mead emphasizes, only exists in reference to a social group (Mead 1934:163-64).

In Mead’s account, reflexivity here takes the form of reflections on one’s role in the group. Mead provides this account using the concepts of the “I” and the “Me”. The capacity for reflection on the generalized other is what Mead calls the “I”: “The ‘I’ is the response of the organism to the attitudes of others,” while “the ‘me’ is the organized set of attitudes of others which one himself assumes” (Mead 1934:173-75), the generalized other presents itself in individual experience as the “me”, as the way one sees oneself (which can only be a culmination of the pictures of oneself formed from the perspective of others). The “I” on the other hand is able to reflect on this cumulative picture and take spontaneous action. Thus, the “I” is the part of oneself that is free and undetermined (Mead 1934:177). For Mead, like for critical realists, it is only because this reflexive capacity exists that one can speak of human sociability. Unlike insects and other social animals, which, at least according to Mead, automatically carry out their social functions (Mead 1934:178-79), humans fulfill their social roles by reflecting on those roles and then carrying out necessary action.

While Mead’s discussion of the I and Me are the centrepieces of his psychology as it is taken up in sociology, the theory makes no specific mention of identity. Rather, the concept of identity is developed in interactionist thought, which builds on Mead’s most important ideas to explain how reflexivity produces identity. Although in this dissertation I use the concept

“identity,” the basic idea of the set of meanings pertaining to oneself as an object is sometimes referred to in different terms, among them the “self” (a poor choice of concepts, since the self refers to a process in SI, rather than a set of meanings) and “self-concept.”

Viktor Gecas and Peter Burke, for example, follow Mead and define the self as a “process of reflexivity that emanates from the interplay between the ‘I’ and the ‘Me’.” (Gecas and Burke 1995:41). Yet, they go further than Mead and define self-concept as “the sum of the products of the self” (Gecas and Burke 1995:42). That is, the self-concept is the “image” of oneself that emerges from ongoing reflections of life experience. Crucially, Gecas and Burke define identity as the part of the self-concept that relates to relationships in a group (Gecas and Burke 1995:42). Gecas and Burke’s definition of identity in these terms is important because it locates identity specifically in group life. In their framework, self-concept is the overarching set of self-meanings, while identity pertains to those meanings that relate to one’s position in a group. Thus, Gecas and Burke’s definition of self-concept roughly approximates the critical realist concept of personal identity, while the concept of identity corresponds to the realist concept of social identity.

Building on Chicago-school symbolic interactionism, authors associated with the Iowa and Indiana schools developed a more structural and quantitative approach to the concept of identity. For example, Manford Kuhn saw the self as a direct product of large-scale social structural process, rather than something that emerged from the contingencies of local, particular social settings and interactions (Gecas and Burke 1995:43). Developing this approach, members of the Indiana school, most notably Sheldon Stryker, but Burke and Gecas included, devised a more explicit “identity theory”, which saw the Self “as composed of a hierarchical set of identities, each of which was tied to roles within the social structure” (Gecas and Burke

1995:44). Also working within symbolic interactionism but departing from the Chicago school in a different dimension, adherents to the biographical and historical approach introduced a more radical temporal dimension into Self and Identity. These authors, Glen Elder for example, “are concerned with the larger cultural context within which selves are constructed.” Influenced by Weber and Mills as much as Mead, such authors focus primarily on biographies as narratives through which a particular conception of Self is constructed (Gecas and Burke 1995:44).

To understand the link between reflexivity and identity as it is conceived in symbolic interactionism, one has to return to two classical thinkers: Herbert Blumer and Anselm Strauss, each of whom explains how reflection on meaning produces self-concepts.

For Blumer, symbolic interactionism is a research programme that though diverse, does contain a main thread. (Blumer 1969:1): it encompasses approaches that take up meaning as their central object, although in a particular way (Blumer 1969:3). Blumer begins by outlining what he sees as the three main tenets of symbolic interactionism. The first tenet is that “human beings act towards things on the basis of the meanings that things have for them.” (Blumer 1969:2). That is, human action is oriented towards a subjectively meaningful world. Secondly, Blumer states that “the meaning of things is derived from, or arises out of the social interaction one has with one’s fellows.” (Blumer 1969:2). Blumer is quick to note that a concern with meaning is not alone enough to distinguish symbolic interactionism from other theoretical approaches. Theoretical traditions like structuralism and psychoanalysis are no doubt also concerned with human meaning. The symbolic interactionist view is unique, however, in its view of interaction as the source of meaning.

Symbolic interactionism, Blumer argues, eschews two of the most common ways of seeing meaning in social and psychological thought. The first, which Blumer calls realism –

though we might also think of it as a kind of empiricism – holds that meaning is intrinsic to the objects one perceives (Blumer 1969:4). In this view, a chair means the same thing to anyone who perceives it, because there are qualities of a chair that always effect the same response in the human cognitive apparatus. Blumer also takes note of the other dominant approach to meaning, which sees it as a product of the human mind. This, of course, is Kant’s idealism: objects of perception derive their meaning from the structure of the human mind, rather than from qualities intrinsic to the objects themselves. For Blumer, the Kantian approach to meaning underlies schools of psychological thought as diverse as the study of attitudes and psychoanalysis:

[The Kantian view] limits the process of the formation of meaning to whatever processes are involved in arousing and bringing together the given psychological elements that produce the meaning. Such processes are psychological in nature, and include perception, cognition, repression, transfer of feelings, and association of ideas. (Blumer 1969:4)

For symbolic interactionists, meaning cannot be taken as the simple product of the solipsistic subject. Rather, meanings are “social products”, which “are formed in and through the defining activities of people as they interact” (Blumer 1969:5).

The third tenet of symbolic interaction pertains to how people make use of meanings, and how, as a result, meaning is actually formed in human interaction. According to Blumer, “(...) meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters.” (Blumer 1969:2). That is, rather than “absorbing” meanings passively, the human use of meaning is active, since each meaning is interpreted before it becomes part of action. This activity can be characterized as a two step process. First, the “actor indicates to [herself] the things towards which [she] is acting.” Blumer emphasizes

this indication is a kind of self interaction, since the act of indicated is a kind of talking to oneself, in which one gestures to an object. The second step, after an object is demarcated, is to fit the meaning of that object to the situation or context in which it is found (Blumer 1969:5). Note that the gap between the original meaning of the object and its context is what provides room for transformation in meaning. If I meet my friend for lunch in January, and he's wearing a winter coat, the original meaning of the coat fits the context: I might think to myself, "that is my friend, he is wearing a coat, coats are for cold weather, it is cold outside" – this requires no modification of the meaning of my friend, a coat or the weather. If my friend were to show up wearing a coat in the heat of July, I might have to get more information about any of the aforementioned objects, transforming their meanings in the process. This discrepancy or gap between meaning and empirical reality is what, for symbolic interactionism, drives social change.

According to Blumer, this view of meaning, largely developed by G.H. Mead, characterizes symbolic interactionism. There are also a number of a priori concepts that are integral to symbolic interactionism's particular conception of meaning. While the three tenets of symbolic interactionism are primary epistemological, these a priori concepts comprise symbolic interactionism's ontology, as they underlie the approach's conception of the social, the actor and the connections between the two. To begin, Blumer defines human society as the collection of inter-connected human action (Blumer 1969:6-9). The important factor in the social is, however, the relationship between individual action and its connections with other actors. For Blumer, social interaction then is more than the sum of the individually motivated actions of its component parts. That is, rather than social interaction being a field where individual instincts, attitudes, repressions and so forth are expressed, the actions of individual actors are directly

oriented to the interaction – human interaction is constitutive of, rather than simply expressive of, the meaningful actions of individual actors (Blumer 1969:10).

Blumer also discusses the “nature” of objects. Objects are things to which actors can refer and towards which they can act (Blumer 1969:10-11). According to Blumer, there are three types of objects: physical objects, inanimate, but tangible things in the world, social objects, which are people, and finally abstract objects, like principles, ideas and laws.(Blumer 1969:10). Objects become common when they mean the same thing to multiple people. At the same time, the meaning of objects is constituted differently according to the interactions in which they become important; this is why “people may be side by side but living in different worlds”; what to me might be a symbol of freedom to someone else could be a symbol of oppression (Blumer 1969:11).

Next, Blumer defines the acting human being. In line with his definition of human interaction, Blumer ascribes a radical sociality to the human organism. While the statement that humans act is certainly true, this for Blumer, can also be consistent with other theoretical views that see those actions as a simple product of other, more important forces, like instinct: “The human being who is engaging in self interaction is not a mere responding organism but an acting organism – an organism that has to mold a line of action on the basis of what it takes into account instead of merely releasing a response to the play of some factor on its organization” (Blumer 1969:15). Rather, for symbolic interactionism, humans are radically social actors because they have the ability to take themselves as objects: thinking is a process of indicating one’s situation to oneself: “a human being can be an object of [her] own actions.(Blumer 1969:12). Human action then, involves the “forging of lines” in the context of this self interaction, through which others are radically taken into account (Blumer 1969:15).



The concept of identity is implicit to Blumer's work, although he opens the door to its conceptualization. If one considers the symbolic interactionist frame, it becomes clear that the reflexive consideration of circumstances, in particular, the idea of indicating one's situation to oneself, requires some internal conception of who, what, when and where the self is. This of course stems from Mead's idea of the Me, which is close to Cooley's conception of the looking-glass self and refers to one's own position seen through the eyes of the other roles to which a person's own roles are connected. Simply put, indicating to oneself requires a point of reference, a set of meanings that locate a person to themselves.

Although today Anselm Strauss might be most well known for the invention of grounded theory, he has also made a number of contributions to social psychology and symbolic interactionism. *Mirrors and Masks: The Search for Identity*, Strauss' first monograph, is his attempt to link the individual and social structure (Clarke 2007), particularly around the notion of identity. In this regard, Strauss builds on Blumer's reading of Mead to explore the implications of the social self. Although he insists on approaching identity an "ambiguous and diffuse term", Strauss mentions that identity "is connected with the fateful appraisals made of oneself—by oneself and by others" (Strauss 1959:9). Identity, then, captures how one sees oneself, which, in the symbolic interactionist perspective, is fundamentally entangled with how one thinks others see oneself. It is also refers to how one is actually perceived by others: that is, an actor's objective location in a social interaction.

In the first chapter, Strauss discusses the importance of language to identity. He begins with the concept of the name, stating that "any name is a container: poured into it are the conscious or unwitting evaluations of the namer" (Strauss 1959:15). For Strauss, naming has two functions. In the first place, to name is to indicate – to identify some portion of the empirical

environment as worthy of attention. Secondly, by naming something, one places it in a particular class of objects, which themselves can only be understood relative to other objects; to name is to “mark boundaries” (Strauss 1959:19). Objects can be constituted as objects – they can be named – in different ways. They can be put in different classes of objects. A knife, for example, can be a weapon in one context and a tool in another. How an object is named depends on the namer: “the way in which things are classed together reveals (...) the perspective of the classifier” (Strauss 1959:20). The perspective of the classifier is itself a social product, in that it is reflective of different forms of social organization; what is one thing in one social context can be an entirely different thing in a different social context. By developing common languages, groups effectively designate social worlds of objects that are relevant to their members (Strauss 1959:21-22). A group, in this sense is a “symbolic fact” (Strauss 1959:149), a number of people who shares a particular social world.

Although Strauss makes this point implicitly rather than explicitly, his discussion of naming is relevant to identity because identities, when taken in a symbolic interactionist framework, are a kind of “social object”, to use Blumer’s term. Thus when Strauss discusses the relationship between objects and action – namely, that the naming of an object sets out the lines of action toward that object (Strauss 1959:22) – we can take this as a description of how identity impacts action. For Strauss, “classification, knowledge and value are inseparable” (Strauss 1959:23). For the person, a classification of what one *is*, is fundamental to an awareness of possible lines of action. Furthermore, this knowledge is evaluative, in that what an object *is* also premised on expectations of what it should be (Strauss 1959:23).

Strauss develops a temporal model of identity: he argues that using language involves evaluating past, present and future actions (Strauss 1959:31). In this regard, action becomes a

stream of evaluation, in which past acts are recalled and put to the service of future action (Strauss 1959:32). This evaluation hinges on the identity of oneself and others, since when a person takes her self as an object, she is judging her past acts (Strauss 1959:32). The constitution of identity, then, is a temporal process. Identities are forged in the life process. While formulating future actions, people recall their past ones, and in the process, develop a sense of who they are: “in anticipating what your act is going to look like to those others who will in turn respond to it, you see your future act as in a kind of complicated mirror” (Strauss 1959:34).

The confrontation with oneself is also a social process, in the twofold way mentioned by Blumer. On the one hand, the self is social because the actions towards oneself have “just as much complexity of acts towards others” (Strauss 1959:33). On the other hand, people seek validation of their self-appraisals for practical and “sentimental” reasons (Strauss 1959:35). In practical terms, actions usually require the cooperation of others. Self-appraisals that accord with the social context are likely to garner that cooperation (Strauss 1959:35). When self-appraisal is out of step, it can lead to uncomfortable re-evaluations of oneself (Strauss 1959:35). Of course, such misguided self-appraisal is endemic to human life: “men, from whose acts temporal categories cannot be separated, make constant mistakes in judging past, present, and future; their lives are marked by comedies and tragedies of error” (Strauss 1959:36).

The potential for error, delusion and other kinds of rejected self-appraisal means that as long as identity is social, it is never entirely safe: “the danger consists in the possibility that one may lose his world and his possessions” (Strauss 1959:37-38). Strauss’ discussion of material possessions here makes it clear that he thinks of possessions as both physical and symbolic objects. When a person or a group loses the symbolic or physical world on which it bases its actions, its members are forced to come up with new interpretations and definitions of the

situation (Strauss 1959:38). Such changes can be individual or collective in scope. A breakup, for example, might force a person to redefine love, just as industrialization no doubt forced craftspeople to shift their views of labour. While people are often committed to their identities, and in extreme cases, will sacrifice themselves (Strauss 1959:39-41), sacrifice itself often marks the beginning of a new identity, premised on the most desirable parts of the past (Strauss 1959:43). Strauss' point here is that identity is always subject to change. Explaining that change is an important task of social psychology (Strauss 1959:43).

Changes in identity need to be understood in the context of interaction, since this is where most self-appraisal occurs (Strauss 1959:44). In fact, it might be more accurate to say that all self-appraisal, at least in the symbolic interactionist view, is a form of interaction. Still, Strauss seems to be speaking here of interaction between two persons rather than interaction between "I" and "me". For Strauss, a key component of interaction is the set of motives that each actor ascribes to the other (Strauss 1959:45). Interactions tend to go smoothly, but if something interrupts the flow of interaction, actors are forced to appraise themselves and the other, making recourse to identity to do so. Actors have to assign "situational identities" to continue the interaction (Strauss 1959:46-48). These situation identities come with imputed motives, which are either confirmed or rejected depending on how smoothly the interaction goes (Strauss 1959:50).

While a "psychiatric" (or more psychological) view would mean seeing these imputed identities as stemming from the particular personalities of the social actors involved in an interaction (Strauss 1959:70), interactionism holds that identities are relative to social groups. That is, the identities that prevail in social interactions are ones that tend to be positioned within a social structure: "Two persons in interaction are never merely persons but group

representatives; a teacher and a student, of given social classes, ages, cliques and the like” (Strauss 1959:70). In this regard, interaction is semi-structured, in that possibilities for interaction are limited within the bounds of the identities in play; “power and influence” determine which sets of identities come to structure the interaction (Strauss 1959:71-72). Strauss calls this ascribing of identities in an interaction “status-forcing” (Strauss 1959:77), in that people are often forced, by the interaction itself, to take on particular identities. For Strauss, then, the adoption of identities is not a limitless, playful process as it is for post-modern thinkers. While social actors do have some leeway in interaction, they are also bound by the rules of the often many identities in effect during a given interaction. Strauss tells us, furthermore, that status-forcing has implications for how we see ourselves (Strauss 1959:82). This is due to the dual nature of identity. On the one hand, it is something that from the subjective point of view, emerges out of daily interaction. On the other hand, identities are not developed from scratch. My identity as a person is also intertwined with the identities of others, as well as more generic identities like “student”, “man” and so forth. The evaluation of past action, and the formulation of future acts, thus occurs in the context of self-appraisals that are based fundamentally on other-appraisals and more general identities that have their own reality *sui generis*. My identities, even in their most personal forms, can, like other objects, only be defined relative to other, social identities.

From the point of view of the person, identities change over the course of a life, and thus need to be understood in the concept of human development. Strauss notes that developmental psychology tries to broach this issue, but tends to see the essential parts of identity “completed” by the end of adolescence. But what about changes to identities that occur in adult life (Strauss 1959:89)? Strauss believes that such changes should be thought of as “careers”, which unfold

through a series of inter-related transformations (Strauss 1959:92-93). Transformations tend to occur at key “turning points” in people’s lives, which can be socially patterned (Strauss 1959:96-100).

*The Realist Response to the Interactionist Conception of Reflexivity and Implications for the Concept of Identity*

While symbolic interactionism offers some useful insights about reflexivity, it also has important shortcomings that are remedied by a more realist conception of reflexivity. There is, in fact, an close link between Margaret Archer’s theorization of reflexivity and the interactionist alternative, although Archer ultimately moves away from a purely Meadian conception of the internal conversation. She traces the conception of the internal conversation from Comte to Mill and then the pragmatists William James, Charles Peirce and G.H. Mead. Through a detailed consideration of the pragmatists, she finds most affinity with Peirce, while she faults James and Mead with under and over-socialized conceptions of the internal conversation, respectively. In the context of this dissertation, Archer’s critique of Mead and symbolic interactionism is most relevant. Even though Mead is often taken as the greatest proponent of the “internal conversation” (Archer 2003:79), the supposedly internal conversation between “I” and “Me” is, in Archer’s view, a conversation between two generalized others (Archer 2003:90). While the “I” appears initially as the kernel of freedom in the inner life of the individual, with the “Me” acting as a kind of censor, the “I” is ultimately deprived of agency. For Mead, the “I” can only arise in situations where this an interruption in the flow of social action, or a disjunction between the meaning intended by the actor and the meaning received by co-actors. It has a primarily adaptive function: to ensure the smooth functioning of the individual’s social life (Archer 2003:88). When the “I” makes demands that put it in opposition to existing society, these

demands are, in Archer's reading of Mead, made in the name of an alternative society (Archer 2003:89). The result is an account of the internal conversation that deprives the individual of all agency, even in her internal thoughts.

Archer uses the concept of reflexivity to explain the formation of personal identity and the determining of personal interests within the grid of situational logics. By Archer's account, human reflexivity is the medium of structural power; for society to enable or constrain the actions of human beings, those beings must be aware of themselves as actors and society as the field of action. At the most basic level, society is only possible because human agents are self-conscious (Archer 2003:19). Despite being critical of G.H. Mead, Archer is in basic agreement with the interactionist assumption that reflexive activity is a precondition of social life (Archer 2003:30). Because they are self-conscious – that is, they can recognize themselves as subjects and objects – people are able to deliberate about and prioritize the various concerns that make up their lives (Archer 2003:27). At the same time, because they can deliberate, they are able to reflect on social relations and thus activate the constraints and enablements of different social positions (Archer 2003:20).

### *Reflexivity in Practice Theory*

While symbolic interactionism is an important foil for the realist conception of reflexivity, realists have also begun to engage with Bourdieu and the “practice theory” inspired by his work. While the concept of identity does not play an important role in Bourdieu's work, there has been a developing discussion around the concept of reflexivity and its genesis. Specifically, some realists have turned towards Bourdieu's concept of habitus as a way of specifying the causal powers of individuals (DeCoteau 2016, Nash 2003:44, Sayer 2011, Sayer 2012), despite Margaret Archer's well-known critiques of Bourdieu and habitus (Archer 2012,

Archer 2010). Realist work on habitus has also been done as part of a “Bourdieuian interdisciplinary cognitive sociology” (Brekhus 2015:16)(2015, 16), where the goal has been to use habitus to demonstrate how the causal powers of habitus, interact with culturally-influenced cognitive processes (Ignatow 2007:122). The perceptual and emotional “residue” that underpins such practical knowledge causes Ignatow and others like Lizardo and Strand to call for an embodied (Ignatow 2007), “holistic” (Ignatow 2010), or “strong-practice” (Lizardo and Strand 2010:209-10) view of cognition, which, using Bourdieu’s concept of habitus, more firmly incorporates the role of the body and emotion in human thinking. Following critical realists like DeCoteau (2016) and Elder-Vass (2007, 2012), Ignatow praises Bourdieu’s theory for its capacity to accommodate a realist ontology (Ignatow and Robinson 2017).

In realist social theory and in cognitive sociology, habitus is used to explain the emergent properties of individuals as distinct from social structure. According to DeCoteau, “to avoid reducing structural properties to their constituent parts (downwards conflation), the concept of emergence becomes indispensable because it allows critical realists to argue that both structures and agents come to have powers of their own.” (DeCoteau 2016:305). In her realist reading of Bourdieu, DeCoteau argues that the emergent properties of agency can be traced to conflicts between primary habitus and secondary habitus as well as the unique cognitive positions offered by being in “interstitial spaces” (DeCoteau 2016:315-17). In cognitive sociology, the realist reading of Bourdieu, and specifically of the concept of habitus, serves the purpose of ontologically grounding the analysis of cognitive structures, so that the interaction between culture and the individual will not become excessively constructionist (Ignatow and Robinson 2017:962). In terms of reflexivity, there has been a growing body of work that attempts to use



Bourdieu's framework, against Archer, to explain the genesis of reflexivity in the dynamics of habitus and social fields.

Throughout Bourdieu's *oeuvre*, the concept of habitus remains relatively consistent as a set of principles operating unconsciously to guide social action. Bourdieu's conception of habitus relies on his conception of social space, his "social topology" (Bourdieu 1985:723). For Bourdieu, the social world can be conceptualized as a series of "fields": "multi-dimensional [spaces] of positions such that every actual position can be defined in terms of a multi-dimensional system of co-ordinates whose values correspond to the values of different pertinent variables." The "pertinent variables" for Bourdieu are economic, cultural, social and symbolic capital – "material, cultural and symbolic possessions able to confer force or power on their holders" (Peters 2012:66) – the "overall volume" and "relative proportion" of which characterize the positions of individual agents, as well as groups of agents, that occupy similar positions – classes (Bourdieu 1985:725). In this way, Bourdieu's thinking "depicts social formations as structured spaces of positions" based on the distribution of capital (Peters 2012:66).

Connecting field to habitus, Bourdieu notes that these "sets of agents (...) have every likelihood of having similar dispositions and interests and therefore of producing similar practices and adopting similar stances." (Bourdieu 1985:725). In *Outline of a Theory of Practice*, Bourdieu defines habitus as "the durably installed generative principle of regulated improvisations"[.] (Bourdieu 1977:78). The habitus conditions the thought and practice of agents such that when they act, think and speak, they do so within the confines of the logic of a particular social field: "Each agent, wittingly or unwittingly, willy nilly, is a producer and reproducer of objective meaning." (Bourdieu 1977:79). Bourdieu uses habitus to account for social coordination: "One of the fundamental effects of the orchestration of habitus is the

production of a commonsense world endowed with the *objectivity* secured by consensus on the meaning (*sens*) of practices and the world, in other words, the harmonization of agents' experiences (...)." (Bourdieu 1977:80).

Later, *In The Logic of Practice*, Bourdieu offers a better-known definition of habitus as "systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them." (Bourdieu 1990:53). Habitus is a mechanism that generates repertoires of behaviour directed towards specific social fields (Bourdieu 1990:53); it "[guides] the occupants of a given place in social space towards the social positions adjusted to their properties, and towards the practices or goods which befit the occupants of that position." (Bourdieu 1979).

Thus, for Bourdieu, the concept of habitus plays an analogous role to identity in the interactionist framework: it is the source of the meanings towards which social actors develop lines of action. There are some crucial distinctions, however, in the concepts. In the first place, habitus, unlike identity, has its roots in psychoanalytic thought and in no way presupposes, like symbolic interactionism, conscious internal conversations about what a particular situation means and appropriate actions within it. Rather, habitus is an ingrained, "feel for the game" that predisposes social actors to pursue some actions and interpretations over others. Moreover, while reflexivity for symbolic interactionists is a relatively routine, basic part of mental life, for Bourdieu, true reflexivity is much more exceptional, and occurs primarily when they are conflicts between habitus and the social fields within which actors find themselves.

Critical realists themselves have been critical of Bourdieu's view of reflexivity as relatively exceptional. The problem, in its simplest form, is that Bourdieu can be read as suggesting that since the habitus contains the necessary dispositions for occupying a social position, social structures are reproduced relatively consistently and mechanically at the level of individual practices. If this interpretation of Bourdieu's work were true, then he would fall into the downwards conflationist camp (in which Archer places him), ceding the powers of individual social actors over to social structure.

Commenting on this problem in the context of critical realism, Roy Nash writes: "socialization theories [of which the habitus is one] explain how people come to be members of their culture, and explanations of their actions or 'practices' in terms of socialization are basically observations that people do what they have been brought up to do." (2003:50). One prominent example of this critique is Margaret Archer's argument that "Bourdieu's concept of habitus [is] an argument for structurally determined 'routine action'," (Farrugia 2013:290) and is thus "downward conflationist" or sociologically determinism (DeCoteau 2016:304). Archer thus lays two charges against Bourdieu: first, that he insufficiently accounts for reflexivity, and second, that habits are no longer relevant in a rapidly changing world of the "reflexive imperative" (Archer 2012:68).

Related to Archer's claim is the set of charges, detailed by Faber (Faber 2017), faulting Bourdieu's thought for being sociologically determinist. Simply put, if one ignores the process through which habitus is acquired, as well as the nuances in his accounts of different types of habitus, Bourdieu's theory appears as a simple socialization theory, focused on detailing how the habits that reproduce a hierarchical social structure are inculcated mechanically in individuals.

The solution to this problem has been to underscore the instabilities in habitus that stem from its temporal and topological nature: it can be “split” across diverse fields and over time. Faber convincingly argues that Bourdieu’s attention to the split habitus in his later career, as well as his casting of the habitus as a set of conditions on “improvisation,” demonstrate that he was aware of, and in fact, quite interested in the unpredictability and spontaneity inherent in the functioning of habitus (Faber 2017:445-48), and therefore not at all inclined to determinism. Decoteau, additionally, argues that “Even if there is a strong *illusio* in a particularly doxic field, each individual person is always situated at the intersection of multiple overlapping fields, with disparate valuations and distributions of capital, which can provide each of us with multiple (and quite often contradictory) ontological orientations and perspectives [,]” thus creating opportunities for reflexive action (DeCoteau 2016:316). Bourdieu himself, in the early *The Logic of Practice* and the later *Weight of the World*, acknowledges the temporal disjunctions inherent in the habitus: “The *habitus* – embodied history, internalized as a second nature and so forgotten as history – is the active presence of the whole past of which it is the product. As such, it is what gives practices their relative autonomy with respect to external determinations of the immediate present.” (Bourdieu 1990:56) Extending this idea to the conflicts contained within the family around the question of legacy and inheritance, Bourdieu writes: “As a matrix of social trajectory and the relationship to this trajectory, the family is necessarily a matrix of the contradictions and double binds that arise from the disjunctions of the disposition of the inheritor and the destiny contained within the inheritance itself.”(Bourdieu et al. 1999:507-08).

Decoteau’s and Faber’s arguments, as well as Bourdieu’s own comments on the habitus, demonstrate that Bourdieu does in fact account for at least two kinds of emergent properties in the habitus 1) the properties that emerge from the interaction between existing habitus and the

demands of a new social field (“vertical disjuncture” (DeCoteau 2016:304)) 2) the properties that emerge from habitus that comes into conflict with itself as people occupy two opposing or conflict fields simultaneously (“horizontal disjuncture”(DeCoteau 2016:304)).

Bourdieu’s account of reflexivity is problematic, especially when it comes to developing a concept of identity for use in empirical work. The fact that the meaning guiding action is largely unconscious and located in habitus leaves little room for the reflexive determination of meaning and identity. Bourdieu explains reflexivity as an effect of dis-junctures, which essentially means that it is an epiphenomenon of social fields. Yet, the interviews about MAiD identity that I conducted as part of this dissertation suggest that identities *are* constructed reflexively, especially in situations when individuals are given the space to do so, such as in interviews. Additionally, adopting a Bourdieusan perspective would mean seeing the pro-MAiD identity as purely a matter of cultural capital in the field of death and dying. In this regard, the principle of autonomy would be a form of cultural capital, deployed specifically to signal and enact a certain dominance in the field of death. While interesting to contemplate, analysis at the level of habitus neglects the variety of meanings of the concept of autonomy, and the way that it emerges from the life histories of the individuals in the study.

### *The Realist Conception of Reflexivity*

Building on the interactionist concept of identity, and moving away from the practice theory of reflexivity, in this dissertation I develop a realist conception of identity, built on, but going beyond Archer’s conception of reflexivity. Archer makes three central propositions regarding reflexivity. Firstly, the main activity of “private, inner life” is “reflexive deliberation” or the determination of “how some item, such as a belief, desire, idea or state of affairs pertains

or relates to [the subject] itself” (Archer 2003:26). That is, while some mental things, such as political beliefs, for example, can exist simultaneously privately and publicly, the consideration of how such beliefs fit into the subject’s life is an entirely private matter. Secondly, Archer argues that even though this private mental life is often unobservable, it is socially necessary (Archer 2003:28-31): “Unless people accepted that obligations were incumbent upon themselves, unless they accepted role requirements as their own, or unless they owned their preferences and consistently pursued a preference schedule, then nothing would get done in society” (Archer 2003:30). Thirdly, this deliberation is not a simple “introspection” or looking inwards “to see what we find there”, but rather, is “an active process in which we continuously converse with ourselves” (Archer 2003:34).

The sum of these propositions is that there exists a private realm of mental life, in which people order their lives through the process of internal conversation. Archer is careful, however, to delimit the bounds of this existence. She borrows from Karl Popper and outlines a “pluralist ontology” in which private mental life can fit. In Archer’s view, reality can be ascribed provisionally to objects which have effects; thus replacing a “perceptual criterion” with a “causal criterion”. In other words, an object can be postulated as real by virtue of an observation of its effects, even if the object itself cannot be directly perceived (Archer 2003:35-36). According to such an ontology, human reflexivity is part of the mental world. We can infer its existence by observing its effects (the ongoing existence of society and the transformation of identity (Archer 2003:41)) without being able to directly observe it from third-person perspective.<sup>32</sup>

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<sup>32</sup> It is important to mention, however, that the mere existence of such first-person, self-knowledge does not guarantee its veracity. Archer notes, in this vein, that first-person knowledge is authoritative only in the sense that people are able to say, more reliably than third-parties, what they believe, and whether or not they believe it. That is, they can be sure about what they believe, even if that belief is false Archer, Margaret. 2003. *Structure, Agency and the Internal Conversation*. Cambridge:

According to Archer, the reflexive self or internal conversation emerges directly from “the components of our mental capacities” (Archer 2003:94) – consistent with ontological dualism, the self exists in the subjective mode, rather than objectively as an epiphenomenon of interaction. For symbolic interactionists the self only emerges once significant symbols have been constituted in social interaction. Archer, on the other hand, sees the self as emerging “from our practical, relational encounters with the world. (...) By virtue of our practices we acquired the ‘object concept’, the first form of conservation, which distinguished each of us from all other things in our environment, including other people” (Archer 2003:39). It is in this sense a “personally emergent property” rather than a social one (Archer 2003:94). In practice, reflexivity takes the form of a temporal alternation between the “object self” and the “subject self” (Archer 2003:99-100). Through an iterative process of deliberation (the selection and consideration of life projects), deliberation (a hypothetical playing out of these projects by the objective self) and deduction (the results of the previous two steps) people carry out internal dialogues (Archer 2003:102-03).

Archer’s account of reflexivity is part of her concern with describing the mediation between structure and agency. Having specified reflexivity, she is able to provide a three-phase model for the morphogenesis of identity that parallels structural and agential morphogenesis: 1) potential enablement and constraints on a given person are shaped by past social interaction, 2) persons order their own concerns towards “nature, practice & society” and 3) persons formulate courses of action by evaluating objective possibilities through discernment, deliberation and

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Cambridge University Press.. This last point is important because it illustrates again that situational logics only act conditionally on individuals. People do not always interpret their life situations according to the logics incumbent in the social position that they occupy. Rather, their interpretation is based on the internal conversation, which is a property of human beings as opposed to social agents.

deduction (Archer 2003:125). In this model, persons themselves are responsible for putting into practice the constraints or opportunities of they face as a agents in the social and cultural structure. Accordingly, social structure never determines the contents of people's minds: rather, internal deliberation is shaped only contextually, by congruency between projects and the social structures that pertain to them. All decisions are ultimately made, however, by active agents. This is why Archer is able to explain the morphogenesis of agency as an interplay between Corporate and Primary agents: she can distinguish between the actions of primary agents, which are more determined by personal reflexivity and its diverse concerns, from those of corporate agents, which by definition are aligned with situational logics. Primary agents introduce an element of unpredictability into group elaboration because they act based on the diverse concerns determined through their reflexivity.

Coming back to the theorization of MAiD, specifically, Archer's identification of the internal conversation and its role in the development of personal identities directs our attention the process of personal morphogenesis that led to the creation of pro-MAiD identity. When discussing the specific identities of the individuals in this study, I assume that their moral identities are the outcome of a reflexive navigation of life experiences, especially life experiences around death, dying and bereavement.<sup>33</sup>

### *Motivation and Concerns*

By including deliberation as the motor of social action, Archer preserves the notion of human autonomy while also including the shaping effects of social structure. Rather than making

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<sup>33</sup> The model of personal morphogenesis has methodological ramifications. That people themselves can provide the best evidence of their own internal conversation, and that their identities are developed through this conversation as it is applied to life experience, suggests a method that can account sense-making. Hence the qualitative, interview method used in the study.



deliberation a black box, however, Archer develops a realist concept of deliberation, to acknowledge the diversity of factors that impinge upon human thinking. Although not intrinsically antithetical to contemporary neuroscientific understandings of cognition, Archer adopts a “weak cognitivist” (Sperber 1997, Strydom 2007): she focuses her conception of cognition on “reflexivity”, rather than making reference to neuroanatomy or physiology and the brain’s information-processing functions. Archer’s approach to reflexivity is closer to phenomenological approaches that focus more on the experience of reflexivity than its bio-psycho-social origins. Nevertheless, she does acknowledge the roots of cognition in the body and the social world. Her concepts of reflexivity and of deliberation encompass influences from several aspects of reality, each which gains shapes deliberation through the medium of emotion.

At a cognitive level, the deliberation of concerns is a process of self-conscious, self-consideration – the subject asks herself, what are my concerns, and what can I do to formulate a life project or projects that are sympathetic to them? For Archer, this process goes back to the universal qualities of human being. In *Realist Social Theory*, she notes that

[b]oth Agents and Actors remain anchored in Persons, for neither of the former are constructs or heuristic devices; they concern real people even though they only deal with certain ways of being in society and therefore not with all ways of being human in the world. Because of this anchorage in common humanity, it will be necessary to complete our account by returning to consider what social identity is thus anchored in, and what difference it makes that it has this anchorage. (Archer 1995:256)

Archer makes this return in *Being Human*, where she argues for a realist conception of humanity to fit her theory of morphogenesis. Archer’s central point in the book is that sociality is not exhaustive of the human condition. Although human concerns do take into account social factors, which is necessary for people to be motivated in social actions, social concerns are not the only ones people have. Reflexivity thus involves an ordering of these concerns, a putting into

relation of problems in the natural, practical and social domains, each which entails a different kind of knowledge (Archer 2000:177).<sup>34</sup>

### *Moral Identity and Morals*

The theoretical frame discussed to this point assumes that people develop identities based on a reflexively ordering of priorities into life projects. Actors use evidence provided directly by their emotions, which are responses to concerns, to orient their actions. Yet, what, if anything, is different about this process when it comes not just to identity in general, but specifically to “moral identity”? Note that medically-assisted death is often, though not always, construed in public discourse as a moral matter. In public opinion polls,<sup>35</sup> respondents are asked if it is “right” or “good” that physicians intervene (with consent) in the dying process. Consider, for example, the 2014 Ipsos-Reid poll that asked respondents their extent of agreement with the

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<sup>34</sup> In *The Internal Conversation*, Archer also makes an empirical argument about three “modes” of reflexivity or internal conversation: communicative reflexives, autonomous reflexives and meta-reflexives. Communicative reflexives tended to be suspicious about their reflexivity, and so relied on a dense network of others to carry out their deliberations Archer, Margaret. 2003. *Structure, Agency and the Internal Conversation*. Cambridge: Cambridge University Press.. Autonomous reflexives, which Archer associates with the upwardly-mobile global middle class, have faith in their internal conversations, preferring solitary deliberation rather than confirmation from a dense network of friends and family. While communicative reflexives tend to prioritize their social networks, autonomous reflexives prioritize social advancement, embodied here in their careers *ibid.*. Like communicative reflexives, they were content with the *modus vivendi* they had created for themselves. Meta-reflexives, on the other hand, had an “uneasy” relationship to their social context *ibid.*. Like communicative reflexives, they put little faith in their own deliberations, but they did not counteract their doubt with external deliberation, but instead “withdrew into self-interrogation” *ibid.*. Rather than being able to prioritize their concerns in a relative fashion, they strive to subordinate all concerns to an ideal *ibid.*; “what they were seeking was holistic – a life wholly aligned – as a living expression of their ideal” *ibid.*. Because the study was focused on analysing the MAiD identity, and not reflexivity types *per se*, I did not operationalize this part of Archer’s theory in the dissertation.

<sup>35</sup> The specifics of this question have varied over the past century. For example, a 1953 Canadian Gallup Poll asked participants “would you approve or disapprove if mercy killing by doctors were made legal in this country?” 1953. “Canadian Gallup Poll, May 1953. #227.” edited by G. C. Inc.. The poll first asked participants first asked respondents “what would you say is meant by the phrase mercy killing?” (a relative majority mentioned that it meant “putting to death an incurably ill person to save suffering”), before asking whether they approved of it.

statement “doctor [sic] should be able to help someone end their life if the person is a competent adult who is terminally ill, suffering unbearably and repeatedly asks for assistance to die.” (2014:1). In news articles, authors sometimes refer to “the ethical question,” or simply “the question.”<sup>36</sup> For the time being, I “bracket the question of whether there is truth in ethics” (Abend 2008). Rather than engaging in debates about whether or not MAiD is morally desirable, the dissertation is focused on an analysis of how MAiD became a moral question for some people in the first place.

Matters are made difficult initially by the ambiguity of terms like “morality,” “morals,” and “ethics,” at least as they are used in everyday speech;<sup>37</sup> a full engagement with the scholarship on meta-ethics is beyond the scope of this dissertation. Nevertheless, it is necessary to establish some definitions. When someone says that the legalization of euthanasia is an “ethical question,” this could mean several things. In the first place, one might mean simply that euthanasia is a social problem, one that needs to be “solved” by legislation. Alternatively, one

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<sup>36</sup> Consider the opening sentence of a 1994 Globe and Mail editorial, which reads, “Anyone who has watched a loved one suffer a lingering, painful death can appreciate the courage of the Canadian Medical Association in tackling the *ethical question* of whether doctors should help desperately-ill patients commit suicide.” 1994. “Let Parliament Decide.” Pp. A20 in *The Globe and Mail*. Journalist Tom Blackwell, similarly refers to “the question” as “[provoking] heated debate across the country.” Blackwell, Tom. 2011. “67% of Canadians Support Legalizing Assisted Suicide: Poll.” in *National Post*.

<sup>37</sup> Sociology has had much to say about normativity, morality and ethics over the past century so. Some would argue that it has always been central to the discipline (Abend 2010, Hitlin and Vaisey 2010, Hitlin and Vaisey 2013). Powell (2010) and Abend (2008) detail the ways this question is taken up by Weber, Durkheim and other key figures in early sociology. According to Hitlin and Vaisey, explicit concern with “morals” and “morality” in American sociology peaked in the 1940s and 1950s before receding into Talcott Parsons’ ideas of moral norms and moral consensus, which were widely critiqued from the 1960s onwards (Hitlin and Vaisey 2013:51-52). One could argue that this concern persisted longer in European sociology, particularly in Critical Theory, where the considerations of morality and ethics were central, from Adorno and Horkheimer’s reading of the descent into instrumental rationality to Habermas’ more optimistic consideration of communicative rationality. The past two decades have seen the resurgence of a “new” sociology of morality (Hitlin and Vaisey 2010, Hitlin and Vaisey 2013), concomitant with a continuing interest in morality and moral issues in philosophy, psychology and cognitive neuroscience, that is focused on the social construction of morality.

might mean instead that it is a moral problem, in the sense that legislation ought to prohibit or permit the practice. In either case, we are dealing with an “ought.” This “ought” is at the heart of things we know as “normative.” Normativity is the quality of having to do with judgements of value, right or wrong, good or bad, ugly or beautiful (Darwall 2001). “Ducks should be purple,” is a normative statement; it contains a claim as to what ought to be. Normativity being a quality of things, it does nothing to tell use the kinds of objects to which it might apply. In a sense, normativity is a linguistic property, it refers to specific kind of utterance.

This definition of normativity, however, is a formal one; it tells us little about what kinds of things might be normative, or what normativity looks like in reality. It makes sense to say that morals, ethics and morality all involve the normative, but we still lack a definition of how those things are normative. Looking at definitions in philosophy and psychology, common themes emerge. In the *Routledge Encyclopedia of Philosophy*, Roger Crisp (2011) points to three conceptions of ethics. First, ethics can be conceived as “the system of value and custom established in the lives of particular groups of human beings (...).” It can also refer to the specific “morality” of these groups, and the moral principles contained therein. This definition of ethics is similar to Gert and Gert’s (2016) definition of morality in the Stanford Encyclopedia: “certain codes of conduct put forward by a society or group (such as a religion) or accepted by an individual for his or her behaviour.” In these definitions, ethics and morality are interchangeable. They both refer to the normative principles, as well as the applications of those principles, held in common in human groups. Meanwhile, the American Psychological Association defines morality as “a system of beliefs or set of values relating to right conduct, against which behavior is judged to be more acceptable or unacceptable.” (2007). Each of these definitions includes reference to the “system” or “codes”; the set of normative principles of a group.

In the first place, morality and ethics refer to normative principles. The philosophical and psychological definitions, however, go beyond logical dicta. They also refer to custom, conduct and behaviour – actions of concrete human beings. That is, we frequently talk about people’s actions – or even their personalities – as good or bad: for example, saying “he’s a bad person,” or “what a mean thing to do,” the latter of which implies a normative judgment about the person’s actions. What I propose here is that we distinguish between the linkage of normative principles and behaviour professed by individuals, and the normative principles, codes, procedures and rules themselves. I define morals as normative principles, codes, rules and other normative propositions, while morality or ethics refers to the application of or adherence to these principles by groups or individuals.

Normative principles, as cultural elements, should be analysed at the structural-cultural level, while personal moralities should be analysed at the personal level. Morals, or moral principles, refer to the set of propositional, normative concepts and logics or procedures available to be known at any given time, in any give place. I maintain here that they are part of the “cultural level” in Archer’s terminology. On the one hand, these encompass “thin” moral concepts like “thou shall not kill” or “stealing is bad.” – “judgements about rightness, appropriateness or permissibility” (Abend 2011:145). The point is not that such concepts exhaust all moral possibilities or that they exclude their counterparts “thou must kill” or “greed is good,” but rather, as part of the cultural level, they entail logical rules, such that “thou shall not kill” is the opposite of “thou shalt kill.” On the other hand, morals also include “thick” moral concepts<sup>38</sup>,

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<sup>38</sup> Thick concepts, on the surface, present a challenge to a morphogenetic framework. After all, Archer is quite clear that logical rules are derived from universal, practical human action, and are thus constant in place and time. Abend’s argument that thick concepts are necessarily attached to a social context flies in the face of Archer’s theory. However, although the empirical referents of dignity or brutality – what these empirically mean – are attached to a social context, the normative, logical constraints that adopting such a concept places on the subject are still binding and universal. For example,

concepts such as dignity or brutality, which contain both a normative judgement *and* an empirical descriptor, such that they rely on particular cultural and social configurations to make sense (Abend 2011:148).

The principle I have been calling “the autonomy principle” functions as a thick moral concept. The statement, “it is your life, therefore you should be able to decide and control how it ends,” which is the central moral proposition of the pro-MAiD identity, only makes sense according to a particular social configuration of death and dying – specifically medicalized death – and is gains its full meaning in the context of a specific set of social relations and life experiences around death, dying, medicine, religion, relationships and more. It contains an empirical observation “it is our life,” which is contextually bound, and a normative prescription – “you should be able...,” the two conditions for thick moral concepts.

Moral principles, like other cultural materials, position socially those who adhere to them. This capacity for positioning acts as the primary causal power of cultural materials. Recall that for Archer, propositional culture refers to things that *can be* known, not those that *are*. In other words, the power of moral principles is only enacted once such a principle becomes relevant. This becoming relevant can happen in several ways. The first is that, for reasons determined on an individual basis, someone adopts a principle. Consider the example of conscientious objection. Due to a pacifist upbringing, and the weight put on pacifism due to second-order considerations, I have adopted the killing injunction. What this means for me, concretely, is that I am now bound, emotionally, to uphold the principle. If I am confronted with

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whatever brutality or dignity empirically mean in any context is independent of the fact that it is illogical to state, without further implied or explicit qualification, that a practice is simultaneously cruel and kind. Morals are thus firmly in the domain of the cultural system.

the opposite, namely, “you must kill,” I will no doubt experience considerable cognitive dissonance, as the logical properties of the original injunction constrain my personal identity. It is up to me to resolve this contradiction. My options, formally detailed by Archer (Archer 1996:159), are:

- 1) Correct the command to kill so that it can be consistent with original injunction against killing. For example, if I were confronted with conscription and commanded to kill the enemy, I could amend the injunction to read “you must kill only if you have no other choice” while certainly entailing some opportunity cost in terms of disobeying orders to ambush, correcting the injunction, at least in my own mind, provides me with a workable morality.
- 2) Correct both principles; “you shall not kill human beings” “you must kill these enemies, which are not human beings.” This of course requires considerable dehumanization of the enemy.
- 3) Correct the first principle: “you shall not kill, unless your life is threatened.”

Thus the individual must reflexively conduct a considerable moral calculus to determine which is best for her given her other commitments and priorities. It is worth recalling too that although reflexive, this process is far from purely intellectual or theoretical. The situational logic that comes with the killing injunction is felt emotionally as a second-order concern, such that, one could simply kill and ignore the injunction, but at the price of guilt. Similarly, one could proudly uphold the principle, at the opportunity cost of imprisonment.

The moral calculus would work differently for agents, in that being collectives, they lack the emotional properties of individual human beings. Nevertheless, the situational logics of these principles also constrain and enable groups. Whereas in the individual case, moral priorities are

worked out through a reflexive weighting of various concerns, group moralities are determined through interaction between corporate agents and primary agents and among corporate agents. By adopting moral principles as part of a morality, agents place themselves under the constraint of the situational logics associated with those frameworks. Archer provides detail about how such a calculus could play out between groups. Taking up the third case, where the situational logic suggests a correction of the first moral principle when two principles are in contradiction, Archer explains the situational conditions that would foster that logic: “The conditional influence prompting recourse to be made to method (3) becomes operative under two conditions. First, when every version of A to be advanced ( $A^1$ ,  $A^2$ ,  $A^n$ , etc.) has met with B (or  $B^1$  etc.) which remains in contradiction with it. Here those protagonists of A who are unwilling to abandon it entirely are compelled to adjust it much more substantially. Second, the same pressure exists when a syncretic formula (...) cannot be made to stick.” (Archer 2003:168). Thus these situational logics act as constraints on the decision-making processes of agents – concretely, organizations and interest groups. As these agents formulate explicit moral or ethical frameworks, they face these logics.

While Archer’s theorization of the cultural level is vital, we can go further by applying the concept specifically to the moral domain, which raises its own complications. For example, what do we make of elements of propositional culture that are not principles? Indeed, principles are not the only form in which cultural truth claims come. What are we to make of metaphor, idioms, narratives, doctrines and manifestos? Such things are no doubt the product of past morphogenetic cycles, but they now stand as cultural artefacts, sets of principles that can be known. They can be logically compared to other narratives. Take for example the metaphor of smooth sailing. If someone asks me how my research is going, and I say “it’s been difficult, but



it's smooth sailing from here," the use of this idiom places me in a conversation position, such that I cannot refer to all the challenging things that lie ahead in my work, without risking appearing nonsensical or at very least insincere on one or another count.

### *Moral Background*

Contemporary work in the sociology of morality shows that thick conceptions of morality have a "moral background" based on their emergence from specific social groups. The moral background, a concept developed by Gabriel Abend, refers to the conceptual, rather than social, context of morals, which includes grounding, conceptual repertoires, object of evaluation, method of argument, metaethical objectivity and metaphysics.

Let's start with the idea of grounding. Abend explains that "the moral background contains resources for people and organizations to address these demands for reasons or grounding. More specifically, it contains resources to address two distinct questions: (a) What makes things moral and immoral? And (b) What reason do you have to do what is moral and, more generally, to be moral at all?" (Abend 2014:34). Abend explains that the "validity" of accounts of (a) and (b) are matters of convention (2014:36). In other words, the status of a moral ground is determined at the socio-cultural level, by the relationships between corporate and primary agents, as well as in power struggles between corporate agents. Individuals and groups have identifiable grounds, reasons that count as morally valid within for that person or within that group.

The next element of the background Abend discusses is "conceptual repertoires," a concept he borrows from Swidler and Thevenot, among others. These are sets of concepts that "enable and constrain first order morality." (2014:37). Abend describes how these repertoires

indicate the boundary between the moral and the non-moral: “to tell the difference, you need second-order criteria about the boundary between the moral and non-moral. And these criteria are not established individually, but socially.” (Abend 2014:38). In Archer’s terms, the mobilization of cultural repertoires to define some issues as moral and others as amoral needs to be analyzed at the socio-cultural level. Although, the situational logics implied by specific concepts within the repertoires constrain the ways that these can be mobilized, the repertoire and its use is determined at the socio-cultural level.

About objects of evaluation, Abend writes that moral evaluation “must be of or about something whose nature makes it capable of being evaluated from a moral point of view. It is a common feature of moral life that things are evaluated as morally good, wrong, admirable, indecent, cruel or humane. Yet, how is it established which things can and which things cannot be evaluated in this way?” (Abend 2014:40) This aspect of the moral background “works as a constraint” on moral evaluations (Abend 2014:43). The question of “how is it established” is about the relationships between groups. Between groups and among groups, it is possible to identify sets of practices that are deemed moral and those that are not. I mentioned earlier in the chapter that the question of whether or not the euthanasia *should* be taken to be a moral matter is bracketed; yet, what comes into play here is the question of *how* euthanasia can be taken as a moral matter. The history of a moral issue, in this sense, needs to include an account of objects of evaluation, that is, where a moral issue fits into the group of objects that are deemed to be moral matters.

Following Archer, the flux in objects of moral evaluation is determined by struggles between corporate agents and between corporate and primary agents. In the context of euthanasia, for example, we can discuss briefly the notion of the “good death.” In 1977 Herman

Feifel described and critiqued the way of dying in the society of his time, where “death and dying have become the province of the professional.” (1977:7). In the same address, Feifel also calls for a re-engagement with the idea of death. Twenty or so years later, the American medical association published a study of physician care of dying patients, called “The Good Care of the Dying Patient” (Webb 1997:48). What is clear from these two examples, as well as the two survey and editorial mentioned in the introduction, is that some time between the 1950s and the end of the century, death became cast as a moral issue, in part as a result of the development of the hospice, palliative care and patient rights movements. Within these movements, a variety of actors contributed to this moralization of death: physicians, physicians’ professional associations, clergy, hospice nurses, psychologists, patients’ families – all were involved in a struggle to define death as a moral issue. In this regard, the fact that euthanasia today can be approached as a moral issue depends on a redefinition of the moral background that occurred earlier in the century, and which now constrains decision-making about the topic.

The next element of the moral background that works at the level of morality is method of argument. Like conceptual repertoires, groups also have conventions about how to make a moral argument: “(...) a society, social group, or organizational field may have a characteristic way of going about addressing moral questions and making moral arguments. (...) What moral method and evidence may be used—e.g., empirical and scientific, introspective, or spiritual and religious?” (Abend 2014:44). Like the other elements we have discussed so far, method of argument is open to struggle at the socio-cultural level. One way of eliminating an opposing moral argument is to discredit its evidential basis; in a sense, this is the kind of thing Karl Mannheim is referring to when he writes about the “particular” conception of ideology, in which the concept of ideology is used to discredit the evidential basis of an opponent’s thought:

The modern conception of ideology was born when Napoleon, finding that this group of philosophers was opposing his imperial ambitions, contemptuously labelled them 'ideologists.' (...) What is depreciated is the validity of the adversary's thought because it is regarded as unrealistic. But if one asked further, unrealistic with reference to what?—the answer would be, unrealistic with reference to practice, unrealistic when contrasted with the affairs that transpire in the political arena. (...) The new word gives sanction to the specific experience of the political with reality, and it lends support to the practical irrationality which has so little appreciation for thought as an instrument for grasping reality. (Mannheim 1936:72)

Extreme as this example is, it demonstrates the political struggles that occur to define the methodology of moral argument.

The last two elements of the moral background are metaethical and metaphysical assumptions. Metaethical assumptions are assumptions about ethics themselves, for example, moral realism, skepticism, and relativism (Abend 2014:48). Metaphysical assumptions are about the nature of reality – space and time – for example, that underlie moralities (Abend 2014:50). Again, these elements support moral principles and judgments. For example, the Christian principle of avoiding is itself underlain by metaphysical assumptions about eternal time, divisions between temporal and spiritual worlds, the soul, and so forth. The framework of the sin is also predicated on a moral absolutism, in which sins are defined by a Church that represents an eternal, omniscient and absolute authority.

### *Moral Identity*

There is a risk of over-emphasizing the constraining of effects of the cultural and structural levels and so descending into the kind of downwards conflation that Archer's framework is designed to avoid. While cultural principles have constraining affects, these are only incumbent to the use of the principles; whether an individual or corporate agent chooses to invest themselves in a moral principle is an entirely different matter altogether. To know how,

why or in what circumstances people are likely to adopt principles, repertoires and grounds requires a look at how morality, a phenomenon at the socio-cultural level, works.

Morality, as I use it here, refers to the ways morals are adopted, manipulated and deployed by individuals and groups to fit their life-projects and experience – in other words, following contemporary social psychological work, morality is a form of identity. At the individual level, we can think of morality as *ethos*.<sup>39</sup> At an individual level, people are responsible for crafting their own moralities, just as they are other aspects of identity. The same can be said for groups, which we can now refer to more precisely as agents, corporate and primary. Although individual morality varies, it is possible to identify commonalities in those moralities, such that we can speak of a group morality. Whether individual or collective, moralities refer to the complex, cluster or configuration of moral principles held by a group or an individual.

In the first place, moralities are comprised of the principles, values and judgments held by individuals or groups in specific contexts. Unlike moral principles, whose meaning can be separated from context (“this is bad” and its translations means the same thing everywhere, even if the substantive content of the “this” or the “bad” varies), moralities only make sense in a social context. When held by a person or group, a moral principle is connected to ideas, behaviours and practices adapted and applied to a social world. In a critical realist framework, it is entirely acceptable to speak of Christian morality, medical ethics, or George W. Bush’s personal values. We can say that individuals hold specific values as parts of their personal identities. In the case of agents – that is, groups of culturally and structurally positioned people – moralities refer to

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<sup>39</sup> In some ways, this is like Michel Foucault’s distinction between moral codes and ethics; the same moral code can be conceptualized, learned, trained and applied in diverse ways Laidlaw, James. 2014. "The Undefined Work of Freedom: Foucault's Genealogy and the Anthropology of Ethics." Pp. 23-37 in *Foucault Now*, edited by J. D. Faubion. Cambridge, UK: Polity Press..

commonly held moral principles; the moralities of individuals in the group need not follow these to the letter. Individual moralities, are the values and principles by which people live, strive to live, or profess to live.<sup>40</sup>

The hypothesis that autonomy is central to the MAiD identity, and that it is aligned with that identity because of a particular set of life experiences, is based on the assumption that “morality affects strategies of action over time and/or in natural contexts.” (Hitlin and Vaisey 2013:54). The main assumption operating here, derived from CR, is that individuals act based on their identities. In this case, morality is one facet, form or component of identity, which orients people’s actions in the normative domain.<sup>41</sup>

Contemporary social psychology provides the justification for this assumption. Working from the perspective of Identity Theory (See Burke 1980, Stryker 1980, Stryker 2008) and inspired from the shift from moral cognition to moral identity in moral psychology spurred by Augusto Blasi’s work (Lapsley and Narvaez 2004, Stets 2010) Jan Stets and Michael Carter have used this conception of identity to build a theory of moral reflexivity. Their research, which

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<sup>40</sup> A question arises here, of whether a person needs to be subjectively aware of values for them to be considered moral values. Vaisey’s dual-process model would suggest that values need not be made explicit to be moral. I would argue, from within the realist framework, that a value needs to be at some point propositional, even if this occurs within the subject’s internal conversation. While the *experience* of deeply held morals, the way they motivate action without discursive mediation, can be automatic, the value must have at some point taken the form of a discursive “thou shalt...,” otherwise it falls outside the bounds of the normative as I have defined it here. This is also consistent with the realist model of social action, which stipulates that social forces are mediated by reflexivity. For a person to truly believe in a moral principle, she must first perceive that principle as true and order it among her other priorities and concerns, such that it becomes integrated in personal identity. Such perception cannot happen unless the principle is at some point made explicit.<sup>40</sup>

<sup>41</sup> From the symbolic interactionist standpoint, all identities are inherently moral: in interactive situations there is a moral imperative to treat others as they present themselves, and to carry out – or at least appear to carry out – the actions appropriate to the roles we ourselves play Goffman, Erving. 1959. *The Presentation of Self in Everyday Life*. New York: Anchor Books.. In my view it is important to distinguish “moral identities,” aspects of identity that refer explicitly to the normative domain, from the normative quality of identity *per se*.

borrowing insights from both the Chicago and Iowa schools of interactionism, is built on Goffman's observation that identities themselves carry a moral weight. Moral thinking, instead of being understood in the context of discursively produced subjectivity, like it is for Foucauldian scholars, or as a self-contained aspect of the psyche, as it is for Kohlberg (Kohlberg 1984), is understood in the context of identity. Carter and Stets note that "Goal accomplishment involves individuals controlling their perceptions of themselves in situations so that their perceptions are kept near their internal identity standards." (Carter and Stets 2011:193). By introducing the concept of "moral identity" into this framework, Carter and Stets theorize that the moral self-concept becomes a kind of goal to be accomplished; provided that the moral identity is "activated" in a particular circumstance, a person will associate themselves with moral frameworks and action that is consistent with that identity (Carter and Stets 2011:195-96).

Although the specifics of control systems theory are beyond the scope of this dissertation, the idea that individuals pursue actions and life-projects in line with their moral identities is central to my theoretical frame. Simply put, I assume that pro-MAiD activities are motivated by pro-MAiD identities, which are developed over the course of concrete life experiences. Furthermore, I also assume, following CR, that autonomy, as a moral principle, has its own constraining force on moral identity. That is, while individuals adopt cultural principles that align generally with the situational logics of their structural positions as primary agents, these cultural principles, once adopted, contribute to subsequent developments of life projects and identity.

In the theoretical frame presented here, autonomy is a moral principle. As will be discussed in later chapters, it contains injunctions about how human beings are, and how they should be treated. The principle of autonomy also shapes what can be called MAiD morality: a

separate, yet related phenomenon located at the level of human beings that develop a certain set of beliefs, some related to autonomy. The rest of this dissertation is an analysis of how this principle of autonomy aligns with life experience to form the pro-MAiD morality or moral identity.

### *Conclusion*

In this chapter, I developed a realist conception of moral identity, focusing on the reflexive appraisal of concerns. I distinguished between the interactionist and practice theory conceptions of reflexivity and identity. While the realist view borrows much from symbolic interactionism, it differs on a number of important points. Most importantly, it sees reflexivity as emerging from a person's direct, practical encounter with the environment in childhood. The consequences of this difference are important. By locating the source of reflexivity in practice rather than in discourse, realists acknowledge the multiplicity of concerns that confront the reflexive self. Identity, in this sense, is not just about group position, but is also but other competencies and concerns. In the empirical portion of this dissertation, these competencies and concerns are discussed, as they lie at the heart of the psychological preoccupations driving people's adoption of the autonomy principle in their moral identities.



## 6: EUTHANASIA BELIEFS AND AUTONOMY

Having discussed the theoretical orientation of the study, we can now turn towards how it fits into existing research on medically-assisted death. The sociological literature on death and dying is vast, and so in the first section of the chapter I adopt a heuristic grid proposed by Glenys Howarth for sorting the death and dying literature. Within this literature, there is attention to what I call the “structural” and “cultural” organization of death, following the realist framework developed in chapter 4. The structural organization of death, and in particular, the gendering of care work plays an important role in the dissertation. In fact, one of the main arguments of the dissertation is that the structural organization of care has created conditions favourable to collective adoption of the autonomy principle, which is an element of the cultural organization of death. The existing literature, especially the literature on the relationship between religion and support for medically-assisted death, provide context for the autonomy principle as it is discussed in chapter 7. In the final section of this chapter, which serves primarily as a literature review, I discuss the ways in which autonomy has been conceptualized in the literature on death and dying.

### *Social Psychology in the Sociology of Death and Dying*

Social psychological questions – including the relationship between moral attitudes, identities, and social context – are addressed somewhat obliquely in the sociological literature on death, dying and euthanasia. In her 2007 survey of the field, Glenys Howarth points out seven main sociological questions about death and dying that are found in the literature. While these range from the analytic and comparative (structural and cultural differences in death and dying) to the normative ((See for example (Cartwright 2000, Dworkin, Frey and Bok 1998, Ogden

1994b, Omoyefa 2007, Somerville 2014, Wilkinson 1995), it is the first two that are most relevant to the social psychology of euthanasia attitudes as framed here:

- 1) “How do experiences of dying, death and grief differ in different societies? What accounts for these differences? What impact do structural factors such as socio-economic status, ethnicity, sexuality, disability and age have on these experiences?” (The social organization of mortality)
- 2) “How do societies come to terms with or deal with the fact that their members are mortal? How do individuals make sense of their mortality?” (The cultural and personal organization of mortality) (Howarth 2007a:2-3)

In my view, these two sets of questions refer to two distinct themes, which, following Archer’s distinction between structure and culture, I term the structural and cultural organization of mortality, respectively. Although it is informed by studies answering the first question, my study falls largely under the purview of the second question. That is, it is concerned specifically with how individuals make sense of the practical aspects of their mortality, like the kind of death they would (implicitly) prefer, in the context of caring for others and in the context of bereavement.

One could focus on social psychology while answering questions 1 or 2. Question 1 is fundamentally about how people’s experiences are shaped by their structural context, which, if one attends to the psychological mechanisms through which the world is apprehended, felt and acted upon, is a social psychological issue. The second question, in its clause about “how individuals make sense of their own mortality,” raises a similar problem: how does individual psychology interface with the world (especially the ever-present existential condition of finitude)? The second question is particularly relevant to the study here, since it deals directly with the idea of making sense of morality. Identity is both the outcome of past sense-making – it presupposes an understanding of who one is, where one is located, and how one relates to the world and others – and, in social psychology, a condition on future sense-making, since it is the

primary set of meanings towards which a person is oriented. Thus, the question of how individuals construct a pro-MAiD identity in the context of care and bereavement is a sub-question of “how individuals make sense of their own mortality.” As will be discussed in later chapters, the experience of care and bereavement is a confrontation with mortality that spurs a process of sense-making, which leads to the development of pro-MAiD identity.

### *The Structural Organization of Mortality*

Although social structure, strictly speaking, is not the focus of this study, information from studies about the structural organization of mortality provide important context. We are interested here in the ways that the experiences of care and bereavement shape pro-MAiD identities. Nevertheless, structural factors set the context for the kinds of social situations in which people find themselves, as well as the concerns and the priorities they have in those situations. As we will see, the burden of care is not equally distributed, which means that it makes people in some structural positions more likely to be carers than others. In this regard, This can be a long-view, macro question, as it is in historical studies of changing death and euthanasia practices, as well as of the political movements related to them (See DeCesare 2007, Frisby 2015, Kemp 2003). It can also be examined at the micro-level. In either case, the first question, when interpreted in the provisory theoretical framework, is a question of how the distribution of social resources in particular positions also entails a distribution of dying, death and grief experiences in those positions, independent of norms and other cultural principles. The question here is how particular social positions carry with them the potential for particular frustrations, joys and worries for the social agents that occupy those positions. The distribution of life chances means that according to structural position, people have different vested interests

and situational logics, as well as varied exposure to different culture resources, the distribution of which is linked to, although not identical too, structure.

There is a significant academic literature looking at how the individual experience of dying, death and grief, as well as representations and attitudes towards death in various forms, varies according to race (Ambrosio and Le Roux 2007), gender (Ambrosio and Le Roux 2007, Broom and Cavenagh 2010, Ergin 2009, Gamliel 2008, Nakamatsu 2009) and class (Allan 2007, Conway 2012, Conway 2013, Erikson and Torssander 2008, Howarth 2007a, Howarth 2007b). Within the frame of CR, we would read these variations in experiences of death according to structural position as a function of the different situational logics and life priorities people have as they occupy structural positions.

Although psychological processes are rarely addressed as an explicit theme, they play an important role in some of these studies. For example, Broom and Cavanagh explain how participants in their interview study of men and women in Australian hospice care linked gender and the dying experience: “Lack of independence was a key theme, and so too was the incompatibility of the ‘slow death’ and the male identity.” (Broom and Cavanagh 2010:872). Some men in the study felt ashamed at their frailty, an emotion they tried to reconcile with their desire for care. Related to class, Conway cites Allan (2007) to illustrate how middle-class “feeling rules” (Hochschild 1983) were rejected by the lower-class bereaved as being inappropriate to their situation (Conway 2012:443). Both of these studies show that the experience of death, either in the first-person or third-person<sup>42</sup>, is variable according to the set of concerns it presents to people in different structural positions.

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<sup>42</sup> Over the course of this dissertation, I frequently refer to the “experience of death.” Experience in this case refers to the ways that death, as a multifaceted conceptual object, becomes relevant to

In research looking specifically at euthanasia, both survey and qualitative methods have been used to analyse the relationship between structural factors and the experience of mortality. The former have included primarily public opinion studies, looking at the structural factors influencing individual beliefs about euthanasia, although there are a select few qualitative studies that take up euthanasia in specific contexts. In the section below, I review key studies of the relationship between social structural factors and euthanasia attitudes.

Public opinion studies (See (DeCesare 2000b, Horsfall et al. 2001) have found “consistent” correlations between race and euthanasia attitudes. Wasserman, Clair and Ritchey offer a social psychological explanation for this correlation, hypothesizing distrust of medical institutions and frustration with healthcare systems as independent variables explaining generally African Americans’ lower support for euthanasia (Wasserman, Clair and Ritchey 2006:264-68). Wasserman, Clair and Ritchey’s findings reveal the need to further understand the ways that the relationship between patients and their physicians, especially around autonomy, shape moral identities around health, illness, and death, especially as this relationship differs according to race. In the present study, no racial data was collected, although several participants self-identified as white or “Caucasian.” Nevertheless, the findings from my study, as will be discussed in later chapters, suggest that the loss of control that a patient experiences when he or she enters medical care, especially as this loss of control is witnessed by carers, can engender a distrust of physicians. Consequently, the dissertation suggests that this distrust and questioning of physician authority might have fuelled pro-MAiD sentiment; the suggestion was that

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people’s biographies. It can refer, for example, to phenomena as seemingly different as reading a book or seeing a film that prompts a person to reflect on her mortality and attending the funeral of a loved one. It can be “first hand,” meaning about the person’s own death, or about the deaths and mortality of others, two things that are intertwined.

physicians could not adequately assess their patients' well-being, or sometimes, were concerned more with advancing their expertise than alleviating their patients' suffering. These findings suggest that distrust for the medical system is perhaps more widespread than Wasserman, Clair and Ritchey's findings indicate, and that more research needs to be done in the Canadian context on the relationship between distrust and support for the legalization of MAiD, especially as this distrust is structurally distributed. The findings also raises questions about who has access to MAiD, especially those in vulnerable situations (i.e. racialized or poor people, as well as those who lack adequate support networks to access MAiD).

Studies have also been carried out on how attitudes towards euthanasia vary according to gender. Results from opinion studies are conflicting, suggesting a need for further study of how gender position impacts euthanasia belief. Although Weiss cites Horsfall et al. (2001) to suggest that "gender has typically not been found to be an important factor [,]" (Weiss and Lupkin 2009:147), she notes that MacDonald (1998), found men to be more supportive of euthanasia, a finding echoed by DeCesare (2000b:272). In a study of European attitudes, however, Jaspers et al found that respondents who identified as men were more likely to oppose euthanasia (2007:263). These conflicting findings, as well as the dearth of conceptions of gender positioning in quantitative studies, suggest a need to further conceptualize gender and emotion in relation to euthanasia attitudes, especially given the role gender was found to play in the aforementioned study by Broom in the experiences of death. Care responsibilities typically fall on women, especially in spousal relationships (Howarth 2007a:54-55).

The findings relevant to the relationship between gender and care are presented in later chapters. Nevertheless, I introduce them briefly here. Many of the interview participants were women and had worked in caring professions. In their caring experiences, these participants were

exposed directly to what they perceived as a loss of identity among dying people. These findings suggest when it comes to gender and support for MAiD, direct exposure to the dying, in a caring capacity, could be a previously unaccounted for variable. Quantitative studies in the Canadian context should be done to test the explanatory power of gender in MAiD belief, before and after controlling for having the experience of caring for the dying.

Education, occupation and other indicators of socioeconomic status and class have received relatively little attention in the literature, despite Howarth's and Conway's efforts to make class a more prominent theme in thanatology. Nevertheless, socioeconomic status (independent of race and gender) has figured tangentially into several studies of euthanasia attitudes. Namely, Jaspers' study of attitude changes in Holland and Cohen's comparative study of euthanasia attitudes in Europe. Jaspers, Lubbers and de Graaf theorize that increased acceptance of euthanasia is related to the historically increasing educational level of the population, and find a significant correlation between educational attainment and support for Euthanasia (2007:461,69). Similarly, Cohen et al find that an increasing level of educational attainment as well as decline of workers in the agricultural sector were statistically significant explanatory variables in a model predicting an aggregate increase in support for euthanasia across 12 European countries (Cohen et al. 2006:664). These studies provide support for the idea that socioeconomic status – measured by education level, occupation, income and indicators, could explain differences in euthanasia attitudes at the individual level. They do not, however, provide information about how socioeconomic status is mediated at an individual level: that is, how socioeconomic status is translated into euthanasia attitudes.

As one participant in my study put it:

Assisted dying isn't about pain. It's about autonomy and control. People who request assisted dying (...) [are] almost always people who have lived their whole lives being in control. They're overwhelmingly educated middle or upper class, tend to be highly disproportionately number of professionals and managers and stuff like that, people who are used to being in control of their own space and who are educated on the issue (...).

Although insufficient data exists at this point on the demographic profiles of Canadians who have to date accessed the legal MAiD procedures, the findings of my study, namely, that control over the dying process is at the centre of the pro-MAiD identity, support the claim that higher socioeconomic status would be associated with higher support for MAiD. The proposed causal mechanism here is that high socio-economic status are associated with identities focused on self-efficacy, control and authority, priorities that would then be carried over into attitudes towards death and dying. This is also supported by the theory of the moral background, which suggests that the concern with autonomy is rooted in a humanist moral background, itself which is predicated on scientific epistemology, which is typically accessible through higher education or other access to cultural capital.

### *The Cultural Organization of Mortality*

While studies about how social structure shaped MAiD attitudes provide important context to the present study, studies about the relationship between culture and those attitudes are more directly relevant. While the first of Howarth's questions mentioned earlier relates to how structure impacts the experience of dying, the second question of "[h]ow (...) societies come to terms with or deal with the fact that their members are mortal," as well as "[h]ow (...) individuals make sense of their mortality [,]" is a cultural one. As such, this question is directly relevant to the present study. From the realist standpoint, it involves interrogating the logical principles – what is held to be true – about death (what Archer calls the “cultural level” – how the cultural principles of a given era impose logical restrictions on thought and action (Archer



1996:143-44)) as well as how social actors use, modify or maintain these principles to achieve social goals (the socio-cultural level). Since death “raises the problem of meaning for human beings” (Howarth 2007a:15), it follows that social groups have death cultures, bodies of principles through which mortality is understood. As such, these death cultures are important to understand euthanasia, as, according to Archer’s theory, pro-MAiD identity will be structured in part by the symbolic resources available to social actors as they make decisions and think in the context of their mortality.

One of the dominant themes in the cultural literature is the disenchantment of death. The concept of disenchantment in sociology comes from Max Weber’s *oeuvre*. For Weber, disenchantment is the effect of rationalization the moral and spiritual spheres:

The increasing intellectualization and rationalization do not, therefore, indicate an increased and general knowledge of the conditions under which one lives. It means something else, namely, the knowledge or belief that if one but wished one could learn it at any time. Hence, it means that principally there are no mysterious incalculable forces that come into play, but rather that one can, in principle, master all things by calculation. This means that the world is disenchanted. One need no longer have recourse to magical means in order to master or implore the spirits, as did the savage, for whom such mysterious powers existed. Technical means and calculations perform the service. This above all is what intellectualization means. (Weber 1946:7)

Debates about the (dis)enchantment of death are focused on whether death is understood primarily through a religious lens or a medical one: in effect, whether cultural resources are predisposed towards value or instrumental rationality. That is, one can see death in terms of a mysterious time and space “beyond” the temporal world, or as a knowable, calculable and relative predictable state of matter. Howarth points to Tony Walter’s (1996) influential typology separating “traditional death”, which is symbolically and practically governed by religious authority, and modern as well as post-modern death, which are part of the domain of professional

expertise and personal choice, respectively (Howarth 2007a:16-17). For Walter, modern and post-modern cultures produce different emotional experiences of death. For example, the modern cultural logic of mourning, which is based primarily on medical and psychological expertise, constructs grieving as a process of letting go – detaching oneself from the relationships which make the death of others so painful (2007:126). Raymond Lee, in another take on modern culture’s impacts on the knowledge of death, argues that although modernity initially featured a disenchantment of death, death is currently undergoing a re-spiritualization (2008, 2004, 2007). Thus he contends that with the advent of parapsychology, New Age spirituality and “Near death experiences” (themselves products of modernity), the idea of death as a biological end – sustained by medical and scientific knowledge – is subverted, replacing a fear of death with a new “optimism” (Lee 2008:748-56).

The Canadian pro-MAiD movement presents some interesting empirical challenges to the existing literature, which call for a reconceptualization and re-evaluation of the disenchantment/re-enchantment debate. In particular, the relationship between (dis)enchantment and autonomy, needs more research. One of the hallmarks of the pro-MAiD movement is its emphasis on personal control, which is sometimes couched within a critique of medical and religious authority. Thus, the idea that death would either be disenchanted and given over to the realm of medical authority, or “re-enchanting” and given over to a new spiritualism, breaks down in the Canadian context, since the pro-MAiD movement presents a largely humanistic, anti-medical vision of death and dying; it is “disenchanted” in the sense of seeing death in secular terms, rational or instrumental terms, but also critical of both medical *and* religious authority.

Consequently, the existing paradigm in the literature, which equates disenchantment with medical rationality and re-enchantment with spiritual concerns, needs to be rethought. The

question of instrumentality, who controls death, for which reasons, and to which ends, thus becomes important, because it allows us to re-conceptualize the contemporary culture around death. By locating the pro-MAiD identity in lived experiences of bereavement and the humanistic world view, the study presented here reveals how the rationalization of death is not predicated directly on a general cultural trend towards disenchantment, but rather, is the product of a process of making sense of death in the context of caregiving in a contemporary medical context, with a humanistic metaphysics and ethos in the background. The study thus contributes simultaneously to a better understanding of disenchantment, since it provides a grounded theory of how disenchantment functions at the micro-level.

Another major theme in social theories of the meaning of death is the issue of “denial,” “repression” or “sequestration.” There is a body work that points to an occlusion of death from social experience, yet authors within it explain that occlusion in different ways. Becker’s influential thesis about the “denial of death” – that “the fear of death is natural and present in everyone” (1973:15) can be contrasted with roughly contemporaneous theories by Philippe Ariès (1977) and Norbert Elias (1985), both of whom, from different theoretical and disciplinary standpoints, explain the occlusion of death from society as the result of a historical process. For Elias, the emotional consequences of this repression are far-reaching: the anxieties around death, which are repressed as a result of the civilizing process, drive people away from direct confrontation with death. The dying themselves face a new, deep loneliness, as their loved ones desert them in their hour of greatest need.

Anthony Giddens also takes up this theme of occlusion in the form “sequestration” (Howarth 2007a:16) – that is, the phenomenon whereby modern morality is relegated to the sphere of personal choice and the self (Giddens 1991). For Giddens, like for Becker and Bauman

(1992), human “finitude” is a fundamental ontological problem (Giddens 1991:48). The relationship between finitude and culture, however, is for Giddens a dynamic one. Modernity has changed the terms in which culture offers logical solutions to human finitude. In modernity, such solutions are to be found in the locus of self-identity, selected by the reflexive individual. Again, this means that the meaning of mortality ceases to be granted by collective symbolic systems – “sacred canopies” (Berger 1969) for example – but rather, is reflexively chosen by social actors from the cultural materials available to them. In terms of emotionality, in the sequestration model, people choose models of emotionality around grieving, death and remembrance based on their self-identities. Consequently, while authors like Walter and Lee ascribe substantive contents to the modern culture of death, Giddens take on the same culture is primarily formal: in short, the modern emotions around death are whichever ones match the self-identity of the beholder.

The pro-MAiD movement poses a direct theoretical challenge to Giddens’ theory of sequestration, and calls for a re-thinking of autonomy. On the one hand, the fact that control and autonomy are at the centre of the pro-MAiD identity suggest that Giddens’ theory is applicable to this case. After all, does the call for “my life, my choice” not beg for the relegation of an important moral issue to the personal sphere? On the other hand, however, the calls for personal control and autonomy are made in the context of a collective social movement, one that has been successful in bringing a critique of death into the public sphere and enshrining a new vision of the good death in law. This paradox suggests that the role of autonomy in the pro-MAiD needs to be rethought: what are the social psychological conditions under which autonomy emerges as a central part of pro-MAiD identity? Furthermore, as this problematization is primarily secular, the dichotomy between personal/secular versus collective/religious needs to be re-thought.

*Religion and autonomy*

In death studies, the orthodoxy is that secularization has shifted death from the religious ethical sphere to the secular (Howarth 2007a:22-23). Death has undergone and continues to undergo, in this view, a process of disenchantment and sequestration. Not only is death removed from religious consideration; it is also given over to the domain of personal choice. In studies of euthanasia attitudes, this has been translated into a preoccupation with religiosity as an explanatory variable. There are numerous studies finding significant correlations between religious affiliation and behaviour and euthanasia attitudes in North American, Western European and Australian contexts (Cohen et al. 2006, Denk et al. 1997, Jaspers, Lubbers and de Graaf 2007, Moulton, Hill and Burdette 2006, Sikora 2009). Cohen et al (2006:666) found a longitudinal relationship between religion and acceptance of euthanasia, where decreased religiosity across 12 countries was a significant predictor of increased euthanasia acceptance. In a cross-sectional study, Sikora found that religious denomination, church attendance and acceptance of a scientific worldview were strongly correlated with euthanasia attitudes (Sikora 2009:42). Hamil-Luker and Smith (1998) and Moulton et al (2006) also found significant correlations between religious denomination and euthanasia attitudes. The general conclusion of these studies is twofold: 1) some religious systems encourage anti-euthanasia views and 2) as the influence of religious ideas decreases, the cultural environment becomes more favorable to pro-euthanasia views.

In the literature, the correlation between secularization and support for medically-assisted death is theorized to be driven primarily by beliefs surrounding autonomy. For example, Sikora theorizes, in the Australian, Christian context, that people form their opinions of euthanasia by applying deductive reasoning based on their religious beliefs. She notes the influence of

Thomism, which “[g]rants exclusive rights to begin and end life to divine agency.” (Sikora 2009:34). In addition to being predictive of euthanasia attitudes in Sikora’s study (through the significance of the scientific worldview, which Sikora connects to the concept of autonomy), the notion of human self-determination is important in other studies. DeCesare (DeCesare 2000a:273) found a significant correlation between support for freedom of expression and euthanasia, while Denk (Denk et al. 1997:104-06,13) found a relationship between respondents willingness to support euthanasia in a particular vignette and the presence of an advanced directive in that vignette, which Denk notes could reflect a “norm of patient choice.”

As independent variables, conceptions self-determination, support for freedom of expression, and support for patient-choice can also be seen as indicators for autonomy. The Oxford English Dictionary offers several definitions of autonomy, related to organizations, morality and individual persons. For individual persons, autonomy is defined as follows: “Liberty to follow one’s will; control over one’s affairs; freedom from external influence, personal independence.” The studies cited above suggest a basic division in worldviews: views in which human autonomy is central, and views in which it is not. According to Sikora, Christian worldviews typically emphasize the power of God’s will, while scientific world-views, by contrast, emphasize the ability of human beings to determine their own fate. Similarly, support freedom of expression, though it does not encompass all forms of autonomy, reflects a world-view in which people are expected to freely express their personal convictions. Finally, support for patient-choice, as will be discussed in later chapters, reflects a worldview where people are seen as having the ability and right to determine the nature and extent of their medical treatment.

An important qualitative study also provides evidence of the relationship between belief in autonomy and support for euthanasia. Baeke et al, in their study of elderly Jewish women’s

perspectives on euthanasia and physician assisted suicide, demonstrate how divine agency over life was one of the decisive factors separating Hasidic and non-Hasidic participants' attitudes about euthanasia; namely, non-Hasidic women believed that humans had autonomy over their bodies, a principle repudiated by the Hasidic respondents (Baeke, Wils and Broeckaert 2011:267). This study demonstrates the importance of the principle of autonomy (divine or human) as a key cultural principle in the determination of euthanasia beliefs, and shows how euthanasia is seen as undergoing the kind of sequestration Giddens identifies: death, according to pro-euthanasia attitudes, is within the preserve of individual autonomy, a matter of personal identity and self-determination.

Illustrating the importance of self-determination from another angle, in a survey study of moral sentiment about physician-assisted suicide, Bulmer, Bohnke and Lewis found that "authoritarianism," as a personal orientation, was correlated with lower support for physician-assisted suicide (Bulmer, Bohnke and Lewis 2017:250). Authoritarian beliefs are the antithesis of the belief in personal autonomy, authoritarianism typically involves the imaginary, conceptual or literal subjugation of oneself and others to a higher power or principle.

The two most relevant recent studies of autonomy and right-to-die belief (Judd and Seale 2011, Richards 2012) look at RtD activism in Scotland, particularly in the FATE (Friends at the End) organization. In each of the studies, autonomy, freedom or control over the end of life features prominently in the concerns of people who are involved with FATE, particularly for those who joined the organization either because they had a terminal illness, or had cared for someone who did (Judd and Seale 2011:235). There is even longitudinal evidence of the influence of beliefs in self-determination on support for euthanasia, with Cohen et al finding

significant correlations between an increase in “permissiveness” (attitudes in favour of self-determination) and an increase in support for euthanasia (Cohen et al. 2006:667).

Nevertheless, the causal mechanisms through which the principle of autonomy comes to influence pro-euthanasia views remain undertheorized in the literature. While Sikora proposes a model based on deductive reasoning, this is somewhat limited. As will be discussed in the chapter covering the theoretical frame, current sociology of morality suggests that deductive reasoning is only one, relatively rare way that people think about morality. More often, moral views are based on fast, automatic cognition, which itself is anchored in unconscious cognitive schemas. In a way, Sikora commits the “scholastic error” (Bourdieu 2003) and assumes that all social actors behave like intellectuals.

The implausibility of the deductive reasoning model is particularly evident when one considers the findings from Baeke’s study. For participants in that study, the choice to not support euthanasia was not something arrived at through the application of a general model, but rather, took the form of an ingrained, emotional response to a moral question: “No (indignant). (. . .) Suicide. No. (. . .) That is suicide. (. . .) Out of the question. Not by means of an injection, not by means of drugs, by no means. You do not decide when you come into the world. You do not decide when you die. You do not ask to be born neither, isn’t it? (Leyla)” (Baeke, Wils and Broeckaert 2011:267)

The other studies about autonomy cited above do not offer theories of how belief in some form of the principle of autonomy shapes beliefs about euthanasia. Nevertheless, there is significant evidence that belief in autonomy is one of the driving factors in support for medically-assisted death and other forms of euthanasia. Given this direction in the literature, the



field of research on euthanasia is missing a prolonged discussion of how belief in autonomy is translated into support for euthanasia.

### *Conclusion*

In this chapter I discussed the ways that the structural and cultural organization of death have been taken up in the sociological literature. In particular, I noted that while there are ambiguities in the literature around gender and support for medically-assisted death, this dissertation remedies some of that ambiguity by theorizing the connection between gender and care. In terms of the cultural organization of death, I discussed how the autonomy principle has been theorized as an effect of the disenchantment of death in modernity or, relatedly, as an effect of widespread secularization in a number of global societies.

In terms of the dissertation, the literature reveals the general context of autonomy. In my framework, I assume that the principle of autonomy, as a cultural resource or piece of “intelligibilia,” is widely available and encountered regularly by social actors precisely because of modernity. In Chapter 2, I discussed the direct historical correlates to the legalization of MAiD – for example the decriminalization and secularization of suicide. The literature shows that these processes changing the way suicide and other forms of death are treated are part of a more widespread, global changes in the meaning of death. Amongst these changes is the opening up of death to decision-making, represented by autonomy. Thus, although it is beyond the scope of this dissertation to conduct a genealogy of the autonomy principle and its relationship to modernity and to death in modernity, I assume that the ultimate source of the autonomy principle lie somewhere in changes to the meaning of death brought on by modernity.

Building on this assumption, the dissertation includes a theorization of the social psychological processes connecting the autonomy principle to the everyday lives of social actors in the field of medically-assisted death. Although the opening up of death to the autonomy principle is explainable in terms of modernity, for example, Giddens' account, which I mentioned earlier in this chapter, the ultimate putting in to practice of the principle is relatively poorly understood. Consequently, I theorize the relationship between autonomy and the experience of death in modernity, at least as this relationship plays out in the Canadian context.

## 7: AUTONOMY IN THE PRO-MAID MOVEMENT: A CULTURAL PRINCIPLE AND ITS MORAL BACKGROUND

The study discussed in this dissertation was focused on how the lived experience of death – through caregiving, bereavement or serious illness – shapes the conception of medically-assisted death (MAiD) for people engaged in activities related to pro-MAiD advocacy. One of the most important findings of the study, one that is a starting point for a critical realist grounded theory of MAiD belief, is that a belief in personal autonomy is central to pro-MAiD identities. But, more importantly, autonomy is central to pro-MAiD identities in part *because* it aligns with the life experiences of people involved in the movement. This finding is consistent with previous studies and reports on the topic, one of which cites “concerns for personal autonomy and freedom of choice of individuals” as one of the main justifications for the legalization of medically-assisted death (Butler et al. 2013:2). In this chapter I begin to advance the hypothesis that people who have provided care for a dying person tend to have witnessed that person lose his or her identity, and that this experience reinforces the desire to be in control of, or to have autonomy during, the dying process. The first step in developing this hypothesis is to show that the autonomy principle is indeed important to the pro-MAiD movement generally, and central to the pro-MAiD identity more specifically. Beyond centrality, we can also trace the ways that the humanist moral background of autonomy conditions the way that it becomes part of the pro-MAiD identity.

The evidence from the literature and in documents from organizations engaged in the MAiD debates suggests that the belief in the right to personal autonomy is implicated in support for MAiD. Within the critical realist frame, the relationship between structure and social action is cast in terms of structure and life projects, where structure enables or constrains life projects. The

centrality of the autonomy principle raises a question of alignment, between the principle of autonomy on the one hand, and the situational logics that emerge from the interface between biographical experience and the social organization of life and death on the other. Simply put, I assume that if autonomy figures prominently in the pro-MAiD movement, it is because it adequately captures, describes or aids in sense-making in the experiences of people who are involved in that movement. In this regard, the realist interpretation is also a pragmatist one: it assumes that autonomy (as a statement of right – people *should* have control over their deaths) is functional for individuals in the pro-MAiD movement. The situational logics that emerge from the experience of death align with the belief in autonomy, such that a framework based on autonomy helps an individual to make sense of her experience of death in some way. In this chapter, I take up the autonomy principle in the context of Canadian pro-medical assistance in dying (MAiD) organizations. I show how it is used within the pro-MAiD movement, and describe its humanist moral background.

### *Autonomy and pro-MAiD Organizations*

The principle of autonomy is evident in the official statements of organizations advocating for legal MAiD worldwide. For instance, the World Federation of Right-to-Die Societies (WFRtDS), an umbrella organization that includes forty-nine pro-voluntary euthanasia organizations in twenty-six countries (including Canada<sup>43</sup>, the US and the UK), emphasizes freedom in its manifesto:

Believing in the rights and freedom of all persons, we affirm this right to die with dignity, meaning in peace and without suffering. All competent adults -regardless of their nationalities, professions, religious beliefs, and ethical and political views - who are suffering unbearably from incurable illnesses should have the possibility of

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<sup>43</sup> The Canadian organizations in the WFRtDS, L'Association Québécoise pour le droit de mourir en dignité ((AQDMD), Dying with Dignity Canada, Right to Die Society Canada) spearheaded the movement to legalize MAiD in Canada.

various choices at the end of their life. Death is unavoidable. We strongly believe that the manner and time of dying should be left to the decision of the individual, assuming such demands do not result in harm to society other than the sadness associated with death.

The voluntarily expressed will of individuals, once they are fully informed of their diagnosis, prognosis and available means of relief, should be respected by all concerned as an expression of intrinsic human rights.

The language about rights, informed consent, knowledgeable decision-making and the expression and exercise of will belie the emphasis on personal autonomy in the pro-MAiD movement. In particular, the idea that “the manner and time of dying should be left to the decision of the individual” is, in essence, the autonomy principle in action in the pro-MAiD movement.

The autonomy principle is shared by the Canadian pro-MAiD movement. To start, the Dying with Dignity Canada webpage has as its motto, “It’s your life. It’s your choice.” Contained within these two terse clauses are important suppositions, principles and conclusions. First and foremost is the sense of a life as something that one owns; it is your life. Second, and no less important, is the assumption that ownership of a life entails the right to choose what to do with it. The language of rights permeates the Dying with Dignity literature. For example, as part of its publications, the organization publishes a pamphlet called “Protect Yourself: Your Rights as a Patient.” The pamphlet outlines a series of rights that amount to the right of autonomy over life and death. Included under the umbrella of autonomy are rights to decide a number of practical issues in end of life medical treatment, including informed consent, having an advanced care plan recognized, having a substitute decision-maker recognized, the right to refuse treatment, and the right to end one’s own life. The byline for the pamphlet reads: “Knowledge is

power. And by learning more about your rights as a patient, you can take greater control of your care.”

The principle of autonomy is also codified in medical ethics, an intellectual field that arose at a time when there was a widespread questioning of “traditional authoritarian institutions and hierarchies.” (Drought and Koenig 2002:115). Formal medical ethics arose in part out of the patient rights movement, which emerged in 1960s and 1970s. The patient rights movement emphasized greater patient voice in treatment decisions and other interactions with physicians – effectively, greater patient autonomy. Led by lawyers, the movement culminated in the development of formal guidelines and frameworks – like informed consent procedures – governing patient-physician interactions, as well as the advent of the direct-to-consumer drug industry (Rothman 2001). Drought and Konig describe the emphasis on patient autonomy in care as part of the “autonomy paradigm (...)[:] a theoretical construction founded on an idealized assumption of patient characteristics and equally idealized assumptions about the provision of clinical care,” which dominated, at the time of their writing, medical ethics and clinical medical practice (Drought and Koenig 2002:115). They continue to note that the “autonomy paradigm” provides a quick fix to ethical problems faced by physicians, especially related to the availability of new, life-sustaining technologies (Drought and Koenig 2002:115).

In the Canadian context specifically, the autonomy paradigm is alive and well, as the Canadian Medical Association’s Code of Ethics and Framework for Medical Assistance in Dying both have provisions about autonomy. The Code of Ethics has a sub-section dedicated to Communication, Decision-Making and Consent. Article 21, of the Code of Ethics, for example, states, “provide your patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of your ability.” In this case, physicians

are encouraged to aid patients in making their own decisions. Article 24 states, “respect the right of a competent patient to accept or reject any medical care recommended.” The imperative to preserve autonomy even extends to cases where patients are not capable of expressing current wishes (Articles 28 and 29):

Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent. (...) When the intentions of an incompetent patient are unknown and when no formal mechanism for making treatment decisions is in place, render such treatment as you believe to be in accordance with the patient's values or, if these are unknown, the patient's best interests. (2004)

Regarding medically assisted death, the CMA proposes, as its first foundational principle, titled “Respect for persons,” that “competent and capable persons are free to make informed choices and autonomous decisions about their bodily integrity and their care that are consistent with their personal values, beliefs and goals.” (2016).

In addition to being professed by corporate agents, the autonomy principle is also echoed by primary agents, among them the participants in my study. As one participant put it, “Assisted dying isn't about pain. It's about autonomy and control.” Another participant notes,

I believe it [assisted death] should be available to any competent person that wants to be euthanized. You don't need to have a pre-requisite, you don't need to have a certain condition or conditions, you don't need a certain amount of pain, physical or mental. You don't need anything other than the fact that you're competent and know fully and completely that you don't want to be alive, for whatever reason. I mean, it's, you just decided you don't want to be alive anymore, that's it

For these and other participants in the pro-MAiD movement, autonomy is one of the main reasons they cite for supporting medically assisted death. Importantly, however, this conception of autonomy is not limited to MAiD itself, but, for many of the participants, describes a general

condition of humankind: “I just assumed that people ought to have the right of self-determination. They shouldn't be compelled to marry somebody they don't want to marry or to , belong to an organization that that they don't want to belong to.” The prevalence of the autonomy principle in the pro-MAiD movement can be seen as the product of interaction between primary and corporate agents. As I discussed in Chapter 2, the pro-MAiD movement is the culmination of decades-long efforts to change the way that death is managed. Particularly important is the manner in which the movement developed, especially in recent years leading up and following the passage of Bill C-16. Organizations like Dying with Dignity and Right-to-Die Society Canada (RTDSC) operate through consultation; they “uptake” the concerns of primary agents and translate this into legal and political action.

For example, in 2018, Dying with Dignity started two public consultation initiatives. The first, entitled “Voice Your Choice” is a response to the Trudeau government’s decision to appoint the Council of Canadian Academies (CCA) to conduct an independent assessment of federal MAiD policy and its implementation. In the Voice Your Choice initiative, Canadians are asked to submit letters to Dying with Dignity, containing their personal stories about MAiD. The letters will then be included as part of Dying with Dignity’s submission to the CCA (2018b). RTDSC Canada also submitted evidence to the CCA, and like Dying with Dignity, consulted its membership to inform the submission. The second initiative was also started in 2018, after Dying with Dignity received a substantial financial endowment. The organization hopes to consult with its members to decide on future priorities and allocations of funds.

These initiatives by Dying with Dignity and RTDSC show that the organizations aim to incorporate the opinions and attitudes of their members and interested publics into their policies and actions. In terms of critical realism and the theory being developed in this dissertation, these



initiatives are evidence that pro-MAiD organizations are corporate agents for people positioned structurally as in favour of MAiD. The presence of the autonomy in the official documents suggests that autonomy is also important to pro-MAiD primary agents. Through a process of interaction, the attitudes and beliefs are translated into corporate agency, and mobilized to effect political and social change.

### *The Secular Humanist Moral Background of Autonomy*

Secular humanism is “a comprehensive, non-religious life stance incorporating: a naturalistic philosophy, a cosmic outlook rooted in science, and a consequentialist ethical system.” (2017) The participants in my study, many of them recruited through humanist organizations, were generally, either implicitly or explicitly, secular humanists. They typically encountered humanism through their parents or discovered it themselves while questioning their religious upbringing. Consequently, the ways in which autonomy is taken up in the pro-MAiD movement cannot be understood apart from the humanist background of the principle. The nature of the moral arguments made in the name of autonomy are shaped by humanism in profound ways, which impact the subsequent use of autonomy for people involved in the pro-MAiD movement. The relationship between corporate and primary agents around MAiD is a feedback loop, where primary agent concerns are documented and used to craft pro-MAiD narratives that in turn provide some of the cultural materials for future pro-MAiD identities. In the theoretical frame chapter I mentioned that the “thick” conception of morals poses a theoretical challenge to CR, since such a conception holds that moral principles gain their meaning from social context. In the classical CR view, however, the logical meaning of moral principles is constant and universal. This problem comes to the fore when we address the question of autonomy, but it is relatively solvable within the framework I set out earlier. While the *logical* relationships between

cultural principles is universal (i.e. the statement “people should have autonomy over their deaths because they have autonomy over their lives” is logically opposed to “people should not have autonomy over their deaths because they do not have autonomy over their lives”), the substantive meanings of those concepts, including the moral background, is context-dependent. In CR terms, the substantive meaning of autonomy can be analysed at the socio-cultural level, as a function of the relationships between individuals and groups – what is typically called, in classical sociology and social psychology, socialization.

The meaning of autonomy for people involved in the pro-MAiD movement is thus determined largely by their identification with and socialization to atheism, Unitarianism, humanism and other related ideological movements. Of course, in CR and most contemporary social psychology, socialization is not treated as mechanical process. People have agency in their socialization. Nevertheless, participants that I interviewed discussed their atheist, secular identities, which also shaped their view of autonomy. In terms of the socio-cultural level, the role of secular groups in pro-MAiD advocacy has meant that autonomy related to MAiD is largely construed in secular terms. That is, when corporate agents like Dying with Dignity and RTDSC consult with their membership to develop policies and craft a narrative arguing for MAiD legalization or increased access to MAiD, they are impacted by the humanist background, since the people they are consulting express the autonomy principle on a humanist background.

Consequently, while the easing of normative and legal prohibitions on suicide, as well as the patient-rights and palliative care movements, are the historical context within which the idea of autonomy became attached to the notion of death, the substantive context of the autonomy principle in MAiD must also be understood in the context of its deployment within a secular, humanist moral background. In the theoretical frame chapter, I introduced the concept of the

moral background, which contains six analytical elements: metaphysical and metaethical assumptions, method of argument, grounding, conceptual repertoires and objects of evaluation.

In the case of participants in the MAiD movement, we can theorize the effect that secular humanist groundings, conceptual repertoires, methods of argument, and metaphysical and metaethical assumptions have on the way that autonomy is taken up as part of the pro-MAiD identity.

### *Metaphysical and Metaethical Assumptions*

The moral background of autonomy in the MAiD movement follows from a particular conception of the universe, as well as a conception of morality and ethics in that universe. The first point to make about the moral background of autonomy in the MAiD movement is that it relies on conceptions of the universe as 1) subject to mechanical forces, but devoid of intrinsic spiritual order, and 2) as morally neutral. Participants expressed these sentiments through anecdotes and general statements about their moral and spiritual worldviews.

The first point speaks to a vision of the universe as a place ordered by natural laws and regularities, yet absent of any overarching, directed order. We can begin with the case of one participant who, while training for the Anglican ministry in her youth, lost her faith in a divine order to the universe. The participant describes her loss of faith in a telling anecdote about the natural order of things: “The focus of it was when I thought about the event of a lion killing a gazelle. It's one event. To one creature it's triumph and yummy lunch, to the gazelle it's terror and agonizing death. They're the same. And I, jokingly used to say that, you know, I couldn't worship a God that designed things that way. I could've done better myself. So, that's how it all kind of came apart.”

The sense of this anecdote is layered. In the first place, we see a separation between the order of the universe, which is mechanical, physical and material – centred on the physical acts necessary for survival – and the subjective meaning of that mechanical order from the structurally positioned entities within it. For the lion, the kill is a victory. It represents satisfaction, pleasure and ultimately, continuance. For the gazelle, the event has the opposite meaning – agony, terror, annihilation. Yet, as the participant sees it, this is “one event,” one insignificant – from the universal point of view – mechanical event amongst the infinite series of events that make up the natural order. In terms of metaphysical assumptions, we see here that the universe is devoid of an intrinsic, universal meaning. In fact, given the mechanical, naturalistic arrangement of forces – predators and prey arranged in a diametrically opposed struggle for survival – a universal meaning is a logical impossibility. Furthermore, and also consequently, we see the absence of a divine being in this world of Hobbesian violence: “I couldn’t worship a God...”. Simply put, the participant found it difficult to believe in a God that would design a world that had such opposite meanings for the beings living in it.

The idea of the universe as a mechanical, natural order was expressed by other participants. Another participant talks about how naturalism influenced her view of MAiD. Although this participant's parents were religious, she speculates that her parents' connection to the Church was more about the social aspects than belief:

My parents would both have identified as Christian, and we attended church, but I believe it was more cultural than spiritual. Like my mother was a musician, and she was involved with playing the organ and singing in the choir, and she was also involved with a lot of the social activities at the church, and if I had to say for instance, why we attended church, I would say for my mother, probably 60% music, 30% social life, and 10% religion. (...) And my dad, I would say it was probably 50% family obligations, social status duty, 40% social life and 10% religion." So, for this participant, the Church as a social institution was more real

than the actual faith. She notes that her parents did not talk much about heaven and never talked about hell: "it was never presented as a real thing.

Instead of a strong Christian emphasis, the participant describes her father as "a naturalist," who early on introduced her to the idea that death was a part of the natural order, or the "circle of life."

In these participants' worldviews, death is an event that is part of the natural, mechanical order of the universe. It has no intrinsic meaning. Another participant summarizes his view succinctly: "I think the order of the universe has been determined by physics and chemistry and other scientific explanations. (...) I don't think there is any meaning to, to life. You're just born, and you live. And after you die, you go to the same place you were before you were born."

These metaphysical assumptions about the universe lead to a metaethical conclusion about human existence that underpins the conception of autonomy: since the universe is devoid of intrinsic meaning, it is morally neutral: "I believe now that [the world] is fundamentally neutral, there is pain, and suffering, of the innocent, built into the world." In a morally neutral universe, morality is derived from human experience and human knowledge. As one participant puts it: "I think that, over the millennia, the accumulated wisdom of our, our predecessors, have given us a lot of foundation for what reasonable behaviour is. And that, the so called 'golden rule' is um, is very valid. That you, you don't do to anyone else what you wouldn't want done to you." Another participant, who described her beliefs as broadly Christian, although she does not attend a church or identify with a particular denomination, also mentions the "golden rule" as the best approximation of a moral code in a morally neutral universe: "This idea of human, of respect for human beings, that so whether it is you know, form of golden rules that you would have in Christianity but also that you have in Kant with this idea of not instrumentalized others,

about doing with others what you would like to be done (...). All of that I think those are principle that have to guide us, as human beings, if not, then we're nothing in way.”

On their own, these metaphysical assumptions mean that autonomy becomes a fundamental condition of human beings. Although there is a law or *nomos* to the universe in the mechanical, scientific sense, humans are, in moral, spiritual and metaphysical terms, self-governed, in the sense that it is entirely up to them to create a meaningful existence. One participant reveals this connection when she states the following:

It feels like a necessity, it feels incredible to... I don't know how you can go through life, by accepting the complete randomness and absurdity of the world. So that's more like an existentialist commitment almost, to something else. (...) I subscribe to this, well existentialist, not just the existentialist but also probably Camus is the one that could see the most as human beings we are meaning seeking, meaning creators, that's what we do, so yeah, for this reason, we're kind of required to go towards something like that.

The idea of being “meaning creators” reveals that at base, in this world view, humans are autonomous creators of meaning in a relatively anarchic (in the sense of not having a deity ordering the universe) space-time.

### *Grounding*

If the universe is devoid of meaning, what reasons do people have to follow the golden rule? Why treat others well? This brings us to the concept of grounding, or the justification for moral behaviour that is part of the secular humanist background of autonomy. Given that the universe is morally neutral, humanist morality relies on the assumption that it is better to be good than it is to be bad. This is of course a tautology, but, being a premise rather than a conclusion, it does not pose a logical difficulty for social action in the MAiD movement. More concretely,

assuming that it is better to be good than bad, in the absence of a good divine being ordering existence, it is up to individuals to remedy what they perceive as bad situations.

Consequently, notions of duty, respect and dignity are mobilized to justify the application of the golden rule in the context of striving to do good. One participant describes how she inherited a sense of duty from her parents, that compelled her to solve problems that she saw in the world:

And I think that now our job is to do the best we can, while we're here, we only get one kick at the can, and that's kind of what made me an activist I guess. I tell people sometimes this story about my father, who was quite an activist. He was a wise man, he was a high school teacher of math and physics, until he got a better job being a physicist, which he liked much better, but we were out in the country once, driving around, and it was night, and my, we drove past a place where a wire, a hydro wire had come down, and there was a flame, moving up the wire from the ground, and my father didn't just say, oh my god, look at that, he scanned the horizon to find the lights of a farm house, he drove up to their door, banged on their door, asked to use their phone, this was before cell phones, this was the 1940s, and uh he reported the problem.

In this account, we see that the participant's father encounters the random event of a downed wire. He does not simply witness the event<sup>44</sup> but acts to effect change. This anecdote hinges on the idea of personal agency in a morally neutral world, of not standing by and witnessing things, but acting to right what are seen as accidental moral wrongs, arising from the state of affairs of the world.

Note that the temporally-limited nature of human existence – an important metaphysical assumption – also leads to the view that one has to “make the best” of life, part of which means taking responsibility for one’s actions and trying to do good in the world: “our job is to do the best we can.” Another participant echoes this sentiment: “I have a belief that I have one life, and

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<sup>44</sup> The opposition to the hypothetical “oh my god” suggests a passivity to the theistic worldview to which the participant is opposed.

I'm living it right now. I'm not living as if I'm going to have something better later on because there isn't going to be a later on."

In terms of autonomy regarding end of life, the absence of divine law and the assumption that it is good to be good mean that people have a duty or responsibility to use their autonomy (in affairs where it can be exercised) to pursue moral rectitude. For example, even birth follows this logic, as, for one participant, birth control is as much a duty as is managing the end of one's life in a responsible manner. The events of birth and death, which in some world views can be attributed to a God, are in this case given to humans: "I want to be in charge of my life, its beginning, you can't return to its beginning, that was someone else's right, but its middle and its end, are for me to decide about." The participant draws parallels between MAiD, birth control and abortion. Birth control and abortion represent a right to control how life is created, which belongs to the potential parents. They also represent duties, as in duties to not bring children into the world when it would be irresponsible to do so. In the same vein, death, the right to control death, belongs to the person who is dying, since there is no other moral force in the universe to govern that right.

For another participant, moral naturalism begins with the idea of valuing human life. She notes that in her view, human life is valuable beyond mere biological life. "The value of human life has to be connected with some subjective to the individual. " For this participant, quality of life is important. It is as if people have a duty to recognize when life is worth living, and when it is not. Denial becomes important in this equation, in that to deny when death is occurring is to open the door to mistreating the dying person: "Quality of life, and when we ignore that, or we deny it, I think we're doing a dreadful disservice to people."



The participant contrasts the idea of recognizing when life is worth living and when it is not with the Christian view of the "sanctity" of life: "I kind of blame religion for that, to some extent. (...) this whole idea that human beings were made in God's image, and life is absolutely valuable, and only God can take life, because only God gives life, and those kinds of arguments." For this participant, Christian religion obscures the truth of life, which is that people are part of a natural order that includes death: "I believe we are, like any other living thing on this planet, we've evolved as part of the ecosystem. If we were meant to live forever, we would have been made immortal, and we weren't. (...) We are meant to go at some point. We need to just recognize that and accept it. We're alive, therefore we'll die, and wringing a last few years, or weeks, or months, or hours, when a person is ready to go, doesn't make any logical sense to me at all." Not only is the denial of death a moral wrong, it is also illogical -- it does not integrate with the self-evident, natural order of the universe, which is nature.

In the most extreme version of the secular-humanist world view, the moral neutrality of the universe creates a fundamentally bad human existence. For one participant, the physical necessities of life create a situation that the participant describes fundamentally as a "bad life." This participant suffers from several mental health conditions, which inform his outlook on MAiD and euthanasia. Since he was a teenager, this participant struggled with substance addictions. Interestingly, like some of the other participants, he was also religious in his early life, and describes one transition point, where he gave up substances and devoted his life to God for a period of time. Nevertheless, by the time he was older, the participant identified as atheist. For this participant, human nature imposes necessities that should be overcome by an ascetic, discipline lifestyle: "I was religious when I was younger, I always, I would read some of hard core, like I looked up to Mother Teresa quite a bit. I liked Saint Francis of Assisi, like living a

simple life, living a disciplined life was always something that I admired. (...) Like, I look at human nature and to me, human nature is like, it's something to be conquered and it's something that overall is not, it pull, it's deceiving, it pulls you in the wrong direction."

The participant is preoccupied with a sense of order in a disorderly, indifferent and bad natural universe:

Overall, I would say, I don't think life is good. And not just human life, even animal life. Like, let's say you came to me and said, 'Look you can be born again. You can choose anything you want to be. You can be a bird, you can be a lion, you can be any form of animal. You can be an alien. you can be a king, a queen. What do you want to be?' I don't want to be any of them. Without doubt. I still have the same issues, I have to eat, I have to do this, I have to age. I've concluded for me, that overall, life, I don't think it's a good life. (...) It's like I notice all the inconsistencies. (...) It's an imperfect life and I hate imperfect things.

For this participant, legalization MAiD is a way of introducing some measure of agency and perfection into life, thus establishing controlling over it. Talking about euthanasia in terms of suicide, the participant says the following: "it's not a nice thing to see, for anybody. So it, you know, doing it where it's like, you know, you explain you're going to do it, you plan it out, you do it legally with a potion, is just, it's not a good ending, but if it's an ending that's going to come anyways, that's a much, much better way of doing it than these so-called backstreet methods."

For the participant, denying people access to an efficient way of ending their own lives is in effect, keeping people in a world that they have legitimate cause to want to leave:

I mean, I can see why people would be reluctant to having euthanasia just easily flowing. But on the other hand, I also don't see why, because why would you want people to be alive if they don't want to be alive? that's another thing, I mean, the world has enough problems as it is, what's the point of having people, it makes society worse, you know? When people are like, you know, they're not happy with their lives and they're living, only are they miserable, they tend to pass that on to the rest of society too. So it's, overall, I would say for sure, it's the best thing to do

is just let people do it... under a doctor's assistance or I mean, I'm also a strong advocate that you should, as long as it's possible, if you're able, you should administer the medication yourself.

The idea of passing misery onto others in society also resonates with the idea of not wanting to be a burden to others or finding the burden of others intolerable.

Despite the last participant's relatively extreme world view, it shares similarities with the other participants' worldviews described so far. Ultimately, in a morally neutral universe (whether this amounts to a good or bad existence is subjective) it is better to be good than to be bad. In this case, being good means exercising autonomy to be as morally right as possible.

### *Method of Argument*

Method of argument refers to the form in which moral arguments are made. In the case of autonomy in the MAiD movement, participants make arguments about autonomy largely in terms of scientific epistemology. In other words, they appeal to evidence and a "reasonable judgement" about reality to make the case for MAiD. There is a tension in this "scientific" epistemology, however. While participants appeal to evidence, they also frequently argued that each person was the best judge of his, hers, or their own experience. Thus, while they appealed to objectivity and evidence, subjective knowledge was also seen significant as a significant form of evidence in their lines of argumentation.

For the participants in my study, scientific evidence was an important way of defining their moral code. One participant, who participated significantly in a prominent Canadian humanist organization, noted the following: "(...) we supported the need for the scientific method to be applied to what is believed. I mean people are obviously very uncomfortable accepting what other people believe simply because they say it's a matter of faith. But, humanists

in general I think feel that there has to be evidence. (...) And certainly the most prominent humanists and non-theists feel that evidence is the, is what distinguishes the religious from the non-religious.” Another participant echoes this statement about humanism. When asked about order in the universe, she replies:

I guess that would be my first thing, is that it can be completely random. You know, things don't have to happen for a reason. It can just be, you know, different physical forces and we're surrounded by all these physical forces. So, it can be random, and it doesn't have to have some altruistic event or meaning in order to make sense. We can make sense of it by how we treat each other and how we treat you know, this place that we live. That to me is really what the essence of humanism is. You know, we look to science to explain things. And sometimes it does, and sometimes it doesn't or sometimes it can and then it changes. And that is all ok. We don't need absolutes.

In terms of autonomy, this means that in a world where people are fundamentally autonomous, evidence, rather than revelation or faith, is the best way of making sense of the universe.

Although, as the participant notes, science is imperfect, people should do the best they can to assess the evidence they have and act reasonably.

Interestingly, more than one participant described their conversions from Christianity to atheism. Apart from the participant who told the anecdote about the lion and the gazelle, another discussed her gradual turn away from Catholicism and religion altogether, and the role that evidence played in that process. She begins by describing her early Catholic background:

Well I guess in, you know, my early formative years as childhood, you know, the spiritual/moral things were, you know, as dictated by the Catholic church. And I realized around the age of 13 that that was all crap. And it's, you know, I sort of, I mean I wasn't able to just walk away from it at that point in time, obviously. But, you know, I didn't pay a lot of attention to it. I did try going back into, you know, into, you know, religion and you know even going into New Age stuff and just none of it ever felt like it was true. And it just seemed that there wasn't a huge basis in any type of reality for any of this stuff. And it wasn't until say, 10 years ago, that I found humanism and went "This fits!" This fits with, you know, with my belief system and with what I had developed as my moral and ethical code.

What is telling in her story is the idea of a “basis in reality.” For this participant, it was important that her belief system matched what she observed to be true in the physical world. The Catholic belief system simply did not match what she deemed to be the evidence around her, nor did it match her own subjective experience of the world. She describes this sense of mismatch as she experienced it regarding morality, and even gender. When asked about the origins of her realization that the Church teaching did not “fit” reality, she told the following anecdote:

That actually occurred when, you know, we got to be around 12-13 years of age and we were allowed to go church on our own without having to go with the family. And I had gone with my brothers and my sisters and some of my friends in the neighborhood and you know, we get there and we are being berated by the usher. (...) And it's like "Wait a minute!" Like how can you be standing here in church and treating people, regardless of how old they are, like this? And it was just like, I lost the disconnect between morality and the church at that point in time. Like I can still see exactly what that gentlemen was wearing. I know what I was wearing. And I was the only one who didn't go into church. I stayed out.

The hypocrisy of the usher in this situation was evidence for the participant that the version of morality being presented in the church was out of touch with reality. Despite her conversion, which began, according to the participant, around the time of the usher incident, she continued to be involved with the Catholic church – she attended Catholic school – until she was older. During this time, she attended a retreat. Her story about her reaction to the retreat also reveals the mismatch between the Church and reality, albeit this time around gender:

I remember one time I had gone on a Catholic retreat for women. And I just found it to be the most morose thing I had ever encountered. I didn't actually, nothing that was being provided in that retreat resonated with me at all. And I left there feeling that that was a complete waste of my time and my money. That it didn't provide me with anything whatsoever. And at that point in time I guess I kind of started reaching out for you know, some of these other things.

Interestingly, the mismatch here is not cast solely in terms of a mismatch between dogma and an objective reality, but between dogma and her subjective experience.

The idea that moral arguments need to be made based on evidence makes the legalization of MAiD particularly important, since, according to the participants, in the past, end of life decisions were made without an evidential basis. As one participant puts it,

The way everything has been structured and governed by a lot of these faith systems is they have been giving control of how we end our lives to something that doesn't even exist. And that to me is morally wrong to make people suffer because of some fantasy. I can't... My morality and ethics can't match those two up. (...) it's the fantasy, the "God" thing. Where there's one super-natural being and it's like "Woah, that's crazy. I mean, you have all of these people here who are suffering needlessly and what does it gain us?" Absolutely nothing, it doesn't do anything for the person who is going through it and it's traumatizing everybody else.

In a universe where evidence points to the absence of the divine, and where people are fundamentally autonomous, surrendering control of the end of life to a deity is a moral affront. One participant even notes that he is “outraged” by the thought that people would be made to suffer because of God, when the “reasonable” assessment affirms suggests that suffering is profane. He concludes with, “I think a lot of reasonable people suppose that suffering is simply the consequence of disease. It's not a divine infliction. And therefore they should be able to say when they have had enough suffering and, and don't want to go on.”

In general, the argument that people should be in control of their own lives relied, for participants, on the use of scientific epistemology and evidence. Nevertheless, subjectivity was also important, as ultimately, individuals themselves were assumed to be able to provide the best evidence about their wellbeing. Consider, for example, the story of the woman who wanted access to medically-assisted death, but could not get it because a physician did not consider her illness to be “grievous and irremediable.” The grievous and irremediable stipulation in the current MAiD policy was a source of consternation for several participants, since it went against

the idea that the best evidence about a person's condition is provided by that person. In the Canadian policy, however, physicians or nurse practitioners are deemed legally to be the only legitimate assessors of a person's fitness for MAiD. One participant describes her concerns about this by recounting the following second-hand account:

No European country in fact requires terminal illness. So, you have to have a condition, and it's usually in medical conditions, in some countries a mental illness is acceptable, and of course some people think mental illnesses are physical, that they're brain disorders, and they may be right. But in any case, it doesn't have to be such a standard thing like cancer or something, it can be some fairly nonstandard things, and the suffering is intolerable to you as an individual, and you are respected and taken...you are the authority on that subject. But there are still some doctors that look at their patient and say, "oh you can't be suffering intolerably." There's a woman in Winnipeg who was COPD [chronic obstructive pulmonary disease] and has terrible panic attacks and goes to the emergency department and they give her Paxil and send her home, they're tired of seeing her. But it's terrifying to be unable to breathe. It's absolutely terrifying. And she has that, but her pulmonologist has given her certain tests, and gotten certain scores, and he says "you can't be suffering intolerably, because you only score at, you know 13" or something on this scale. That's really, really, arrogant. And some doctors in Europe still do that, but many do not. It's not nearly common there as it is here. And, the suffering is, the patient or the person is taken as the authority on that subject.

This anecdote reveals a paradox at the heart of the humanist moral epistemology. While scientific evidence is assumed to be the gold standard of argumentation, it is assumed that this evidence should not be used to override the subjective evidence provided by the individual about hers, his or their own condition. Hence the frequent qualification to the pro-MAiD argument: "I mean if, if a, if a person is religious and feels that somehow their atoning for the evil things they've done in their lives by suffering, well they should feel free to do that [,]" the suggestion here being that if a person deems that it is in her best interest to confront mortality in terms of the divine, she should be allowed to do so.

### *Conceptual Repertoires and Objects of Evaluation*

Taken together, conceptual repertoires and objects of evaluation establish criteria for objects that are considered in the realm of the moral, and those which are not. This is a relatively classic distinction in sociology, which parallels others cognitive frameworks, such as the sacred and the profane (Durkheim 1995), or the unmarked and the marked (Brekhus 2015). The humanist moral background of autonomy thus includes within it a framework for distinguishing between the moral and the non-moral in the context of medically-assisted death. For the purposes of the theory being developed here, we can see the appropriate objects of moral evaluation as following from humanist conceptual repertoires, which align with the other elements of the moral background discussed previous. The metaphysical and metaethical assumptions of humanism – i.e. the mechanical universe, the duty to moral cultivation and the use of scientific epistemology – establish a set of concepts, including autonomy, that are used by people in the pro-MAiD movement to define MAiD as a moral issue.

In effect, the pro-MAiD movement is another chapter in the historical moralization of death. Death has been, at various times, both sacred and profane. Hence the recent debates in the sociological literature about its disenchantment and re-enchantment (Lee 2008). The participants in the study spoke of the ways that saw death as a moral issue. Common to their stories was the idea of a moral shift, from a society that denied (Becker 1973) that death was a reality, to one where it was recognized as an inevitable fact of life.

It is worth quoting here the motto of RTDSC: “Realism, Responsibility, Respect.” Realism is the concept that connects the humanist moral background with a grid for evaluating the normative dimensions of objects, including death. For people in the pro-MAiD movement, as was discussed previously, the universe is a mechanical order, where humans have a



responsibility to use scientific epistemology to acquire knowledge that can be used to make moral decisions. In terms of the things that are assessed as moral in this framework, another paradox emerges: almost anything is potentially a moral issue. That is, nothing is held to be too sacred to relegate to the realm of human autonomy, since that realm extends over all of life.

The humanist background is most evident in how participants perceived the difference between the objects of evaluation of people who subscribe to humanist beliefs, and those who did not. In general, participants constructed their moral view in opposition to two other groups: professional physicians and Christian churches or devout religious people. Participants saw these groups as not seeing death and suffering in the same moral terms as themselves. The humanist view of suffering, in particular, follows logically from the other aspects of the moral background, like the mechanical view of the universe.

In the humanist moral background, suffering is inherently meaningless. From the anecdote about the lion and the gazelle to other discussions about suffering that will be discussed in later chapters, suffering in death is generally something to be avoided by exercising autonomy and accessing MAiD. We can revisit the participant's statement about how suffering is the consequence of disease and not a "divine affliction." Nor is suffering something to be endured for the sake of preserving the illusion that a condition can be treated when, in fact, it cannot be. In this regard, participants distinguished their "realistic view" from the overly-optimistic professional medical view, where all conditions were potentially treatable, and where suffering was acceptable if it occurred in pursuit of this goal. One participant discussed the conflict between these two moral frameworks – one in which suffering was acceptable in the context of the pursuit of medical technique, and one in which it was not. Her grandmother had anemia, and

physicians recommended repeated blood transfusions. The participant recalls her mother's reaction to the treatment plan:

(...) so my mother started saying, okay, is she going to get better? The doctor's like no. So then she says, so you're going to give her blood, but you gave her blood before, and it didn't help. Well no. Are you going to have to keep giving her more blood? Well, yes. Keep in mind, I would have been about 16. So then my mother looks at him, and she says well she's 85, and she's not getting better, and you're going to have to keep giving her more blood, and she's never going to get better. And the doctor said, she's putting him in a corner, right? (...) My mother says then that's it. No more blood because I'm not going to prolong this. She said this is just ridiculous. She's not getting better, and look at her, she's suffering, and she said I'm just not going to consent to anymore blood because it's not serving any purpose. It's not going to make her better. (...) Then the doctor told my mother that my grandmother was going to die, and it would be hurtful.

The participant highlights the conflict that emerged after he mother attempted to question physicians' decisions to continue treatment at the cost of making the patient suffer. Consider another participant whose grandmother had a similar prognosis. In this case, the participant himself was responsible for making a medical decision on behalf of his grandmother.

"Your grandmother is not very well. We want to give her some blood." "Okay, do you need my consent?" "Yes, because—" whatever the reason that they needed my consent for, they couldn't reach my mom. I said, "Well, because she's out of the country." So, I said, "What is this going to do?" and they said "Well, improve her life." I said, "Okay, for how long?" "Well, we don't know." I said, "Well, what else is it going to do?" And they couldn't give me a straight answer. And I said, "Well, why don't we simply don't give it to her?" and they said, "Well basically, that she's going to just pass away." And I said, "Fine, that is what my mother and father had said is to be done. Do not give the blood." And a physician overheard me and basically something like, "Well, don't you believe in miracles?" And I got into an argument with him saying, "Whether or not I believe in miracle, why is it a miracle will only occur if we give a blood transfusion? Why can we not have the miracle without the blood transfusion?" I basically got a nasty look from the staff and that was the end of it. (...) And after that, I went up to visit her and one of the nurses made a remark about "You know, your grandmother seems to be doing better." And I said, "What do you mean?", she said "Well, her hemoglobin's up." And I said, "Well of course it's up, you gave her blood." I said, "She's still not responsive, but her hemoglobin's up." And she died the next day. I mean it the sort of thing that really bothered me that "Okay, here's somebody that we're going to do something

for that's not going to give them any improvement in quality of life." If it's just going to be quantity, why are we doing that? That's unnecessarily. It's not fair to the patient, it's not fair to the family. The person's wishes were clearly stated, they should be respected and leave it at that.

In this anecdote we see a clash between the humanist moral background, which is based on the assumption that suffering is inherently meaningless, and the professional medical background, in which suffering is an acceptable risk for the chance of a cure or even a short-term extension of life. Given there was no chance of a treatment, the patient refused medical treatment, since at that point, his grandmother's suffering was senseless.

In these cases, the humanist moral background makes suffering meaningful only insofar as it is a temporary bad to be endured if the patient will have a good chance to have a better life in the future. Participants discussed physicians as taking a different approach, where biological life was to be prolonged as long as possible, regardless of the suffering endured. Another participant who was faced with making a medical decision for her husband, who was dying from cancer, describes this conflict:

I just remember when he [her husband] was in intensive care and he was on ... At the time, he was very, very ill and on life support. I just saw his eyes and ... Sorry. That just is a bit emotional. I knew he wanted me to stop it all. (...) I said to the surgeon, "We gotta stop. We gotta leave him." They wouldn't. They wouldn't. The surgeon ... I said to the surgeon, "You know, he wants to go. You've got to let him go." The surgeon said, "Well, all I know is if I love somebody, I'd do whatever I could to keep them alive."

We see in this anecdote a conflict between the participant's wish, which was to cease treatment, and the physicians', which was to continue treatment at all costs.

### *Conclusion*

Because of their connections to atheism, Unitarianism, secularism and humanism, participants of the study and those in the broader pro-MAiD movement generally developed their

pro-MAiD identities, including their belief in personal autonomy, on the moral background of humanism. In terms of metaphysics, the principle of autonomy was based on a conception of the universe as devoid of intrinsic meaning; events happen at random or according to scientific laws, not by divine ordinance. In terms of the metaethics, the humanist view of the universe lead to the assumption that it is “better to be good than to be bad,” and so people had a duty to use reason to assess the best course of action in their lives.

In terms of autonomy, the way that the principle is applied and taken up in the context of physician-assisted death is shaped by the meeting of the moral background with the life experiences of people in the movement. In other words, people adopting pro-MAiD identities adopt the principle of autonomy because it fits the experiences they encounter over the course of their lives. Paradoxically, however, their perception of those experiences is shaped by the humanist moral background. The assessment of congruency between the principle of autonomy and life experience happens within the framework of the humanist moral background. In the next chapter, I begin to discuss this fit between the autonomy principle and people’s life experience around death and bereavement.

## 8: EXPERIENCING DEATH I: CARE AND THE LOSS OF IDENTITY

In the previous chapters, discussion was focused on developing the theoretical framework, introducing the historical context of the pro-MAiD movement, and introducing the humanist moral background in which the autonomy principle is applied to pro-MAiD identities. In this chapter, I begin to discuss why the principle of autonomy, especially in its humanist background, resonates with people in the pro-MAiD movement. Seen from the opposite angle, we can pose the question as one about the motivations of participants in the study: what common features of their biographies compelled them to take up the cause of the pro-MAiD (and the autonomy principle), especially in the framework of the humanist moral background?

In the preceding chapters, I began to theorize the autonomy principle as a causal condition on the development of the pro-MAiD identity. In this and subsequent chapters, I examine the “intervening conditions” – the secondary, contextual factors located in life experiences – that encourage people to take up the principle of autonomy in the first place. One of the hallmarks of critical realism is to avoid reducing complex social phenomena to a single level of explanation (agents, structure or culture) and to show that social facts are produced through a conjunction of factors at the agential and structural levels. In other words, while we can identify a main cause of a social phenomenon, for example, a configuration of social structure or a personal motive, social factors, when seen through a critical realist lens, always gain their actual causal power through a conjunction of structure and agency. They thus always involve what Strauss and Corbin call causal and intervening conditions. Causal conditions are “the events or incidents that lead to the occurrence or development of a phenomenon.” (Strauss and Corbin 1990:100). Intervening conditions, on the other hand, “*are the broad and general conditions bearing upon action/interactional strategies*. These conditions include: time, space,

culture, economic status, technological status, career, history, and individual biography.” (Strauss and Corbin 1990:103). Based on these definitions, we can see the autonomy principle as the main causal condition structuring the development of the pro-MAiD movement and its identity. Yet, the variety of social circumstances that make identification with the autonomy principle possible and even desirable for living, breathing and acting social agents – the intervening conditions – are just as important to developing a plausible theory of the pro-MAiD movement. Without the causal condition of autonomy, one misses the central organizing concept of the pro-MAiD identity; without identifying the intervening conditions, however, the theory becomes cultural determinist, and mistakes the process whereby people identify pro-MAiD as simple socialization.

Consequently, although autonomy was one of the main reasons that participants cited for their pro-MAiD beliefs –this belief in autonomy was developed through exposure to a set of life circumstances. Primarily, it was developed in the context of doing care work, especially for dying people that were close to the carer. As Sandra Martin details in her exposé of MAiD, the legalization movement is largely driven by baby-boomers and the looming healthcare crisis facing them: a drastic increase in the number of senior citizens requiring care and an increasingly stretched healthcare system (Martin 2016). The healthcare and ageing problem is perhaps the most direct historical context to MAiD, which sets the stage for the confrontation with mortality that occurs in care work, and the subsequent pursuit of autonomy.

In critical realism, cultural and structural forces only gain causal powers when they become relevant to actors’ life projects. As actors confront structure and culture, they enact it, avoid it, or resist it, actions which become relevant for the transformation of culture and structure over time. One important question is why this autonomy is so important to participants in the

study. I mentioned in earlier chapters that critical realism offers a general theoretical frame for the work presented here, and CR helps us approach this question. One of the hallmarks of the CR conception of the properties of specific objects is that they are emergent and relational (DeCoteau 2016). That is, the properties of any specific object are not essences, but rather causal conditions that become active once that object is related to other objects. Margaret Archer details this process for social structure, where social structure constrains action when the life projects of social actors fall under the domain of structural conditions. The same can be said for cultural principles – they only become constraining when they become relevant to specific fields of action for specific social actors. Consequently, the question of why autonomy can be rephrased in the CR frame as a question of life projects, and specifically, to which life projects or goals does the principle of autonomy become relevant in this situation?

In terms of emergence, structure and culture take effect when they become materially relevant or resonant with people's lives. The principle of autonomy is codified in bioethics and professed frequently by the lay population in favour of MAiD. Nevertheless, it remains to be shown why autonomy is relevant to the life projects of the people who cite it as a justification for their moral views.<sup>45</sup> Why does autonomy become part of life-projects for the group of people in favour of MAiD? There are no doubt many factors contributing to the resonance of the principle of autonomy to people in favour of MAiD. In my study, however, caring for others emerged as a prominent lived experience that grounded people's conceptions of autonomy. In this chapter, I examine one of those factors: the experience of perceiving a loss of self and identity in another person, primarily over the course of caring for that person.

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<sup>45</sup> The question is relevant not only to the explanation of moral belief in general, but also to the relation between agents (people who are in favour of MAiD but remain unorganized, uninvolved, and silent on the issue) and corporate agents (the organizations that advocate for different aspects of MAiD and represent patients and others in legal cases).

Specifically, I look at how the concern with autonomy emerges from the experiences that people involved with such organizations have had with care and support of the dying. I focus on how a person's enactment of autonomy, as a cultural principle, is mediated by the experience of doing paid or unpaid care work for relatives, friends and spouses. Autonomy becomes a causal condition because it presents itself as a solution to the problem of maintaining self and identity in the context of modern death and dying.

Indeed, this experience of doing care work is important not just in the Canadian context, but globally, where it has exposed an entire group of individuals to the hardships of dying in the modern context. Thus, while the experience of doing care work is not a necessary nor sufficient condition for a single person to identify themselves as pro-MAiD, it does, by participant accounts, expose the person to the experiences of others who are near death, or contemplating their end of life. My findings are thus consistent with Judd and Seale's study of FATE members:

It appears that the personal experience of dying and death exerts an important influence and the extent to which such views are related to personal experiences of others' dying and death, in contrast to similar views expressed by patients for whom dying and approaching death is a lived experience invites further scrutiny. Fear of loss of control, unpleasant symptoms, loss of dignity, and concerns about being a burden on others, all influence members. (...) The experience of seeing distressing deaths in others, the perception that the provision and quality of health care is too often inadequate to address the suffering experienced by some people, and the concern to plan for the future, has clearly led to a decision to take preventive action. (Judd and Seale 2011:238)

Yet, the question arises, what exactly is it about others' deaths that is distressing? What is the nature of the suffering that these carers witness in others? The theory must account for the link between the centrality of the autonomy principles and the experience of doing care work. By approaching the distressing nature of the death of another person, we can begin to uncover the ways that these deaths are experienced and made sense of, and, more importantly, the ways that the principle of autonomy fits that sense-making. Grounded theory analysis of the narratives of



pro-MAiD people reveals that the experience of doing care work related to death and dying exposed carers to the loss of self in others, which, for the carers, was the nexus of meaning within which the principle of autonomy emerged. The chapter begins with a brief theorization of the concept of doing care work and discussion of how participants related to it in their discussions about MAiD. Next, I turn to the primary way that autonomy is presented as a logical solution to the problem of losing the self, and the ways that the humanist moral background shapes this presentation.

### *Doing Care Work*

Although there are differing ways of conceptualizing care in the literature, the most basic definition includes activities that require taking on the “burden of dependency.” Harrington Meyer, Herd and Michel define care work broadly as “providing for basic needs (...) in moments of dependency.” (Harrington Meyer, Herd and Michel 2000:2) Similarly, Moss, Boddy and Cameron note a prevalent definition of care, proposed by Daly and Lewis, where care for others is conceptualized as “activities and relations involved in meeting the physical and emotional requirements of dependent adults and children, and the normative, economic and social frameworks within which these are assigned and carried out.” (Daly and Lewis, 1999, cited in Moss, Boddy and Cameron 2005:6). Although the second part of Daly and Lewis’ definition makes the concept of social care exceedingly broad, the first clause, in which social care is about meeting the needs of dependent others, captures the basic sense of social care or care work: fulfilling emotional, physical and social needs in a relationship of dependency.<sup>46</sup>

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<sup>46</sup> In the North American context, much of this care, while originally undertaken in the public sector, has been shifted to the private sector and to the private home, where it falls disproportionately on women (Abel and Nelson 1999:4-5, Armstrong and Armstrong 2008:11). Many of the participants in my study, like the Scottish activists in Judd and Seale’s study (Judd and Seale 2011), had been care workers at some point in their lives, working in long-term-care facilities. Out of the thirteen participants in my

For the participants in my study, doing care work was one of the central life experiences that shaped their views on MAiD. While participants often recalled the first time that they became aware of the pro-MAiD movement (for many of them when they first read or heard in the news about the Sue Rodriguez case), they were typically first exposed to the issues around physician-assisted death when they witnessed someone else's dying. When it comes to people's views about medically assisted death, the experience of doing care work – being in the position of caring for another, dependent person – shapes how they see death and dying. This is equally true for varieties of care, ranging from relatively minor logistical and routine support with daily activities, to more intense forms of physical and emotional care. It is also true of care that occurs in formal settings, in hospitals, or informally in people's homes. Regardless of the setting, duration or context of care, it typically involves “both instrumental tasks and affective relations,” (Abel and Nelson 1999:4). That is, carers complete tasks for their dependents, as well as engage in emotion work and emotional labour (Hochschild 2008, Hochschild 1983). That caring involves both tasks and affective relations is important, since, without acknowledging the affective dimensions of care, one runs the risk of missing the impact that such relating has on people who support legal MAiD.

In my study, the ways that participants did care work varied; the varied care relationships, in turn, were linked with different degrees and types of emotional connection to the persons receiving care. Regardless, care work caused the carer to confront mortality. For some, this care work was paid, for others unpaid – for some, it was both. It encompassed formal and informal care for parents, grandparents, friends and spouses, and people in varying states of dependency. There was a contrast between cases where participants provided low-intensity care and those

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study, only three were men. Considering the gendering of care work, it is unsurprising that doing care work surfaced as an important aspect of the pro-MAiD identity.

where they provided more intensive care, and contrast between instrumental and affective care. Participants who cared for less dependent persons described the connection as what could be termed empathetic, while participants who cared for more dependent persons described the connection in terms that seemed to resonate more with sympathy.

The connection between doing care work and having a pro-MAiD morality hinged on the reaction carers had to those receiving care. I characterize these differing reactions as empathetic and sympathetic, depending on their form and intensity. Empathy, which “refers to the attempt by one self-aware self to comprehend un-judgmentally the positive and negative experiences of another self,” (Wispé 1986:318) is associated with role-taking, and the cognitive act of imagining how another person feels in their circumstances. Sympathy, on the other hand “refers to the heightened awareness of the suffering of another person as something to be alleviated.” (Wispé 1986). In my discussions with carers, they recounted different ways of connecting with the people under their care, and described how these experiences shaped their views on MAiD. In one case, a participant described her connection with the person under her care in terms that resembled an empathetic connection. In multiple other cases, the connection was described in terms that resembled sympathy.

One of the ways that participants described care was in terms of simply discussing end of life and its logistics with people close to them. Since Kubler-Ross’ ground-breaking research (Kubler-Ross 2005), psychologists, nurses, physicians and sociologists have recognized that dying is much more than a biological end. Rather, dying is a biological, psychological, spiritual and social process, one that has varied, complex and multilayered meanings for the person undergoing it and the people around him, her or them. For people near death, being able to find meaning in their lives – spiritual, moral, social or other – is an important part of the process.

Consequentially, safe, supportive spaces are required for dying people to explore the meanings of their lives (Lewis 1983, Miller et al. 2005). Consequently, discussing end of life with a person who is near it, can mean providing an important form of care. These interactions, especially when a carer has no formal training or is unprepared, could potentially impose their own affective cost.

Participants in my study described the affective work involved in helping loved ones make sense of the end of life. On the low intensity end of the spectrum, one participant describes how she helps her father deal with the logistics of his bills and utilities:

I find it annoying that my father talks about his own death constantly, and I have to go through (...) [the] water and electricity system (...) on a weekly basis for what to do (...) once he's [her father] is dead, with the house and how to shut down the water. But I do it because I think I see oddly enough, that's what he's worried about, like who's going to shut down the water. So if it makes him feel better that I shut down the water, then I'll shut down the water.

In the first place, this kind of logistical, instrumental care work occurs regularly, imposing a weekly time burden on the carer. Yet, it also involves a subtler, more affective kind of work. The participant also refers in another instance to her father having chosen his own grave and having had it erected in a cemetery in advance of his own death, and how his frequent thoughts and plans around death disrupt family plans, and notes her thoughts on her father's preoccupation with managing his death: "I don't, except for the mild annoyance, I don't think it affects me that much, because I think I understand, I understand him. I, I understand what he's doing, what he wants, and it doesn't seem crazy to me. It seems, actually, very reasonable." The participant understands her father's management of death as a natural reaction to winding down a long life. Nevertheless, her "mild annoyance" also suggests that she does engage in affective work while interacting with her father. Managing her annoyance becomes a necessary part of care, as she has

to manage her own feelings to provide her father the space to psychologically manage the end of his life.

The participant explains how this informal care work shapes her view of MAiD. She says, “I think it’s [voluntary euthanasia] something that should be authorized and clearly legislated. I think that (...) here my position comes from personally, and in this case it’s about my father, who feels very strongly about it. Because he is very close to death, he’s definitely very saddened that it is not legalized [where he lives].<sup>47</sup> And it’s a source of incredible fear.” The care work undertaken by the participant, although being relatively detached, in that conversations with her father frequently occur by telephone, nevertheless involves empathizing with her father, and working through the conditions of his death. In this regard, empathy itself becomes a kind of affective work, necessary to productive conversations about the logistical aspects of the end of life.

Other participants also described the logistical aspects of dying that required them to provide affective care to their loved ones, especially parents. One participant describes her father’s worry about money, and her efforts to reassure him that his financial affairs would be looked after:

He worried a lot about the money, and he assigned it all over to my sister. I'm not good with money. My sister works, like she was an office manager at a grain company, and she's more into that kind of stuff. So when he started talking to me about power of attorney, he's worried about that. He wanted to make sure all his affairs were in order because he knew my mother was ... I just looked at him, and I said Dad, I will look after you.

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<sup>47</sup> This participant lives in Canada, although her father resides in a jurisdiction where medical assistance in dying is not legal.

The care being provided here is both instrumental (the tasks of arranging for accountants, setting up power of attorney) as well as affective, in that the participant actively reassured her father that his affairs could be managed well.

In other cases affective work arose around more directly approaching questions about death and mortality. For example, one participant described a conversation he had with his mother about managing her death, as well as the possibility of an afterlife: “(...) I in fact can remember decades ago, my mother saying to me that if ever she were ill, she would not want to be kept on life support. (...) And I remember a few years, she died about, she died in 2004, and I remember a couple of years before she died she said to me ‘there isn’t anything after you die, is there?’” At first glance, being told about someone’s wishes or listening to their beliefs about the afterlife does not appear inherently affective. Yet, for the dying, these concerns are important to being able to accept their deaths and often evoke a certain emotional intensity for the listener, since doing so requires confronting one’s own mortality, as well as one’s connection to the dying person. The participant continues: “And that, that made me think about it at the time. And certainly to recognize that I would , have similar wishes.”

The participant’s affective work extended to the moment when he had to make an important medical decision on behalf of his mother. His mother received dialysis treatment for some years. When she was eighty-five, however, surgery was required to continue the treatment:

She was 85 and her doctor said "you know, she needs another-" there's a place where they have to connect her to the dialysis machine that's in her chest and they said "you know, she just doesn't have tissue strong enough to sustain this". The doctor said "I don't think it'd be a useful thing to have the operation". And at first I thought "oh, I'm not sure that, if I want to let her go in this way" but , eventually it was up to me to tell the doctor that I thought that my mother would not want to have this excessive treatment that might cause her a lot of distress and so on. And so she passed away.

Aside from the personal upheaval, distress and hopefully, growth, that occurs with bereavement, the participant also had to do affective work to make what he knew was the right

decision for his mother: “I would call it emotional reflection. Because you're only going to have one mother and, I, I suppose it was just, it just came upon me suddenly. So that I had to think about it for a bit. And, take, really realize what I needed most of all was to take her wishes into account.” The participant describes his struggle, between not wanting to lose his mother, and following her wishes. He ultimately, through affective work, resolves the struggle and is able to make an ethical decision. Furthermore, the participant’s engagement in care happens with humanist metaethics in the background. The participant believes there is no afterlife, and in this universe absent of divine reason, his mother’s care, as well as the determination of her death, was “up to him;” he acts as his mother’s delegate.

Similar confrontations with mortality happen for those involved in more direct, instrumental care work. In terms of paid care work, one participant recounted her career history, which, tellingly, is punctuated by unpaid care work: “I started working, just a helper and a healthcare aide and stuff like that. I went to [University]. I took nursing. (...) I worked at (...) the biggest teaching hospital here (...). Then (...) I had two babies, and I quit for a bit. (...) [Now] I work on a rehab floor, stroke rehab, but it’s mainly a long-term care facility.” The participant also told me that she worked periodically in a palliative care unit. She also revealed that her interest in nursing began at a younger age, and affected how she approached caring for her grandparents:

Anyways, [my grandfather] was there [in the palliative care unit] for about two months (...). So I used to visit him when he was there, and I used to go there and feed him and help him get washed. Actually, for both of my grandparents, (...) I was really into the ‘I’m going to be a nurse’ thing when I was a teenager, and when my mother’s mother was sick, in the mid-seventies, I used to go to the nursing home, and I used to help wash and feed and toilet her and stuff like that, and I did the same thing for my grandfather.

For this participant, care work is, and has been, a regular part of her life. And even though the instances of more intense care that she discusses lasted from only a few months to a couple years (her time caring for her grandfather and her shifts in the palliative care unit, respectively), an ethos of taking action to care for others is part of the participant's identity:

What I remember about when my grandparents were deteriorating and needing help was I would just go in there and help. I would go to the nursing home and feed my grandmother lunch and then lift her on and off the toilet. I used to get stares. I can remember some of the staff looking at me, well you don't need to do that. And to this day, I have to tell you, as a nurse, it drives me crazy when families come and visit and sit at the bedside and do nothing, and then look at me and say my mother's fingernails need cutting. Well fuck you, can't you cut them?

Here we see the moral background coming into play, as the participant sees it has her duty to alleviate suffering, maintain patients' dignity, and to a certain extent, the elements of their personal appearance that go into making identity.

The participant describes the intense emotion that accompanied this time caring for her grandparents and even her mother:

I think the hard part for me isn't the death, it's the deterioration. It's seeing somebody that's close to you become ill and suffer and decline and not being able to be who they were. So that was the hard part with my grandma. Honestly, I would have to say with everybody in my family who has died, by the time they're dead, I'm done. And then people are all, 'oh I'm so sorry, I'm so sorry.' I can remember when my mother died, I was actually angry. (...) I was even a little bit angry with the people who were offering me condolences, because I just felt they didn't get it. Because she died a horrible death. (...) My frustration and my grieving and my tears were long, long before my mother passed away. And by the time she was dead, I was just relieved. I remember with my grandmother, it was very similar. The hard part was watching her sick and in pain and delirious and not herself and crippled up and immobile.

We can see the humanist background in action here, as her mother died what the participant deems a "horrible death": meaningless suffering, that could have been avoided.

Again, the participant notes that she responded to these intense emotions by intensifying the care she provided:



I felt the only thing I could do was to do what I could, which was to help. Which is why I went in and did that stuff, and the same with my grandpa. I would just go in and help feed him and stuff like that because I thought, well, I'm not going to not do something. I just felt like I couldn't sit there and sit on my hands and act stupid. I just had to do something. (...) I guess the challenge was trying to find something constructive to do and deal with my own emotions of watching the physical and mental deteriorations.

This participant's confrontation with mortality takes the form of sympathy. Thus, the participant cites the experience of witnessing her grandmother's suffering – and experience that spurred her to action. Unlike the participant who cared for her father from a distance, and in a relatively healthy state, direct physical and emotional care for people in advanced states of deterioration provoked a more affectively intense response from carers, which, by their account, led directly to providing additional care.

Another participant, who worked as a nurse for ten years, describes the same process, albeit in the context of caring for a stranger over the course of paid care work. She cites one episode as being particularly important in her understanding of MAiD:

I remember one instance in particular; 79-year-old man who had advanced cancer all through his abdomen. We had this shiny new surgeon at the hospital where I was doing my training. No, actually, that was right after I graduated. (...) He told the family he could save him with a (...) procedure. (...) It was basically taking out significant parts of major organs, and patching the rest together, kind of a straight pipe almost from the throat to the anus. It's a lousy quality of life, even if you survive the surgery. I nursed him in ICU for about two weeks after he'd had the surgery, and while he died even more slowly, because now we have all the life support stuff going on, right? I was really angry about that. (...) There was a lot of recognition, certainly by myself and my colleagues, that there's a time and a place to be supported by life, and there's times and places where we should be supporting death.

Like the participant who cared for her grandparents and parents in their last days, this participant was responsible for providing direct care to someone in an advanced state of physical degeneration. Despite being in a subordinate position in the hospital hierarchy, she acted in conjunction with others nursing staff to advocate for the removal of the surgeon from the

intensive care unit. Again, in this case sympathy for the dying man caused the participant to confront the question of death, and, by her account, shaped her opinion on MAiD. Her sympathy later extended to her mother. She describes her anger at witnessing her mother's suffering in one instance, and her efforts to procure more appropriate care:

When I walked into the hospital room, she was, at that point, throwing up dried blood, and was extremely dehydrated and ill. I have to say, I just about lost my mind. They got a hold of a doctor, and he wouldn't talk to me, but I'd already told him which orders I wanted for her. She needed way better, she needed Morphine. She needed it IM or however else they could give it to her. She wasn't in any shape to take oral anything. She needed and NG tube. She needed fluids, just for comfort measures. (...) We were certainly expecting, demanding, encouraging the hospital staff to give her as much pain medication as she could have.

In the cases discussed in this section, the care work, informal and formal, direct and indirect, paid and unpaid, exposed carers to some of the problems of mortality. They empathized and sympathized with those for whom they cared, and this identification was one of the factors that shaped their view of medically-assisted death. In the cases described above, empathy and sympathy caused carers to identify with the people for which they were caring.

### *Control Over the Timing of Death*

Through their experiences doing care work, participants were exposed to the problems of dying over a prolonged duration in modern medical settings. These experiences shaped how they put autonomy into practice, as the experience of caring for someone who had little say over their death was concerning. For the participants in my study, like some of those in Richards' (2012:17), autonomy meant being in control of their own affairs, and in particular, the time and manner of death. The meaning of autonomy, for these participants, was shaped by their experiences caring for others, just as it was shaped by the secular humanist moral background. Thus, while autonomy is a causal condition on their support for MAiD, it was shaped heavily the intervening condition of doing care work. As I describe in this section, participants talked about

being in control in terms of being able to decide when a person dies. Importantly, this issue of being in control arose around the issue of doing care work, where one of the main fears of participants was that, during dying, they would lose control over the dying process and consequently, the capacity to enact and express their selves and identities.

While carers sympathized with the physical pain of those receiving care, the principal “bad” for the dying is represented as a loss of control, especially over the course of a prolonged death. The bad death is represented as 1) an interruption to a life, a pre-mature break in something that was meant to continue for some time (the early death), or 2) as a prolonged process, where a person lingers to a point where she loses her self. Participants talked about their desire, and the desire of people close to them, to be able to decide when and how to die. In this sense, questions of timing, location and circumstances pre-occupied participants as they discussed the idea of being in control. Speaking about a friend’s living will, one participant wrote that the will expressed a sentiment of being content with what that person had done, seen and become. Both critical realism and the life course approach (Elder 1994, Elder and O’Rand 1995) in sociology suggest that individuals have “agency” or autonomy in determining their life trajectories. For critical realists such as Margaret Archer, people make decisions about their lives in the context of social structural constraints. Part of this agency, when it comes to death, involves determining when and how to die.

### *Early Death*

When it comes to caring for others, the participants’ experiences caring for other people exposed them to prolonged deaths, which they deemed morally wrong. Early deaths too, were undesirable. Early deaths figured prominently in some participants’ pro-MAiD morality, as well

as in the Supreme Court's ruling on MAiD. One participant summarized this idea while talking about the idea of having video advance directives:

If they could see the former you, alert and saying, "I know I can be happy for the first little while despite my dementia." Demented people are often quite happy in the first stages, in a cute charming sort of way before they start to wander, before they can become prey to one of the negative emotions, which they usually do eventually. But uh, they can see, the real you. The former you, saying, I'm not ready to die just yet. And I don't want to be forced to die earlier than I really want to die, so I'm asking you to respect me to the extent of, being a little uncomfortable, looking at this face I might have two years from now, two months from now, I want you to do it anyway, and here I am, the real me, telling you, asking you, please do this for me. So I can live a little longer, and I will enjoy it for a while.

The participant's reasoning resonates with the British Columbia Supreme's court 2015 decision:

It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.

The Supreme Court's reasoning suggests that under a suicide prohibition, the person faces retaining their autonomy, but at the cost of losing the chance to live out the rest of their good days, or getting to live out the good days at the cost of suffering the inevitable bad ones leading up to death. The court's decision, as well as the participants comment on "draining the glass of life," reveal that the one dimension of autonomy is being able to effectively time the end of life. Participants do not want to be forced to end their lives "early" and miss out on the suffering-free time that is left to them.

For example, one participant contrasts the "natural" cycle of life and death with a death out of joint:

The most significant [death] would be my mother in law. Who died early and from serious illness, from cancer. (...) Of course, also, you would have my grandparents, my grandparents passed away. (...) it was more expected. They were old, they

passed away, they weren't really sick or anything like that, it's just more, it's expected. (...) [They] were older, so it's more kind of life as usual, life and death as usual." The respondent continues to describe the sense of unfairness she felt at her mother-in-law's death: "You're just wondering 'why'? You know, why does this happen to her? (...) Why? Why at this time?"

In this case, we see that there is a sense of a person dying too early, out of joint of the natural cycle of life and death. She contrasts the bad, early death, with her father's death, which she sees as fitting in the natural "cycle":

(...) I would be very saddened when it happens, and I do worry, but once again (...) he's going to be ninety, it is more like life and death as the cycle. And he himself, that's exactly the way he sees it. (...) I guess I'm trying to say, it's not that traumatizing. And yeah, I mean, contrary to what people have no control, like my mother in law, where it tends to be much more traumatizing.

### *The Prolonged Death*

In general, the prolonged death figures prominently in the pro-MAiD movement, especially for people who care or have cared for others undergoing a prolonged death. In a famous blog post, Gillian Bennet, a retired philosopher and psychotherapist diagnosed with dementia, discussed and justified her decision to kill herself. Writing about her desire to remain autonomous, she notes the following:

There comes a time, in the progress of dementia, when one is no longer competent to guide one's own affairs. I want out before the day when I can no longer assess my situation or take action to bring my life to an end. (...) I would not want some unforeseen complication to mess up my decision to cost Canada as little as possible in my declining years.

The sense of Gillian's statement is that her main fear is to be deprived as the decision to leave or not to leave her life. While Gillian Bennet does not cite care work as a motivation for her views, participants in my study experienced the prolonged deaths of loved ones, an experience that shaped their views on autonomy.

The sense of dying too late – having a needlessly prolonged death – is thus also important to people more directly involved in care of the dying. For example, the participant who empathized with her father's death referred to the idea of suicide being desirable as a way of maintaining "control" over one's own life: "Getting old, that if you know you can't get out, that they won't let you, it's an incredible source of fear. (...) not that I want to idealize suicide, but there is something quite tempting about being in control." Other participants cited their time working in long-term care facilities and palliative care wards as one of their first encounters with death and described the challenges of working with patients who were undergoing a prolonged death.

One participant, whose time working in long term care involved caring for "people in comas hooked up to feeding tubes, Alzheimer's patients (...), [the challenge was] to give them as good a life as possible, treat them like they were all there, even if they were in an altered state from my norm[,] sympathized with those under her care. For her, the prolonged death is particularly resonant. Recent scholarship on sympathy has shown that people are more likely to sympathize with those to whom perceived social distance – similarity in terms of social and life circumstances and characteristics – is minimal (Churcher 2016, Loewenstein and Small 2007). The participant was diagnosed with a chronic, degenerative disease, and "became determined to make sure I didn't end up in a space like I was working in. (...) My own diagnosis is irreversible and instead of having a few short years of the symptoms, I could have another painful 20 years, where it could also progress and I could end up like those in long term care." The participant in this case sees a long death, particular in long term care, or under similar conditions (suffering or not being "all there") as a death that is too long, instead preferring a "few short years" of

fighting the disease. Her view that people should be able to end their lives before they reach that state is thus shaped by her sympathetic experience caring for others.

Another participant echoes the sentiment of not wanting to live a life too long. She too worked in long term care:

So I've seen some palliative care, and I've seen some long term... I don't know what terminology you use, but I've seen enough chronic care for a lifetime. (...) Somebody, for instance, a typical patient there, might be somebody who, for instance suffered a bad heart attack, or stroke, and really didn't wake up, but the family refuses to accept that they're not going to recover and doesn't want them turned off. So they end up with a tracheostomy and a tube feed and cared for in chronic care like some kind of vegetative patient (...).

Later in our interview, the participant expressed the issue of being in control over the end of her life: "It's the control thing, like I said. If I were in my dad's position or my aunt's position, I would want the option, and I'm not saying I would have used. I just want to know that I have that ace in my pocket that I can pull out and say I'm done, I've had enough." The participant had a number of reasons for wanting to be able to end her life on her terms, principally, her humanist worldview and her experiences doing care work: "So I guess my worldview is a big part of it, and then my life experience with my experiences with people that I've seen die. I mean both in my family and at work." From her statements, however, it seems that the idea of a long death is unappealing and would constitute a bad death.

Another participant describes her father's experience dying at home, in which he was unable to time his death to his liking. Circumstances in the anecdote were slightly different from some of the others, since the participant's father died in the United States. Still, the anecdote reveals that these concerns about having control over the timing of death transcend national boundaries. The participant's father wanted access to medical assistance to die, but, partially because of the religious mission of the organization from which he was receiving hospice care,

and partially because of financial limitations, he had to wait two to three weeks to see an assessor. In most jurisdictions where MAiD is legal, patients must go through a rigorous assessment process, which is designed to ensure that they are mentally competent and thus can consent to the procedure. The various barriers to the man accessing MAiD meant that he suffered a prolonged death: “I don’t know if you’ve ever watched somebody die, but it was awful. It made all our memories like, I didn’t even recognize. I could barely recognize him and I had seen him three or four weeks before. Relating to the timing of death, the participant had the following to say: “(...) if he could have had the medically assisted dying, he could have said his goodbyes. He could have chosen his time because there was no way he was going to survive. Like, he was dying. There wasn’t... that wasn’t... there was no chance of a miracle cure or anything.” In this case, we see that MAiD is important to this participant because it meant giving her father control over when he could die.

It is clear from these accounts that one dimension of autonomy is control over the timing of life and death. However, there is also a second dimension of autonomy, related to the physical, mental and conditions of decline. Not only do people want to “get out” before they are no longer capable of being able to decide to do so; they also want to be able to end their lives before they are no longer in control of their mental and bodily faculties. There is a desire for a primary autonomy – being able to decide – to the end of securing a second-order autonomy: control over the development of self and identity in the final stages of life.

The conception of the good death as a well-timed death, and the desire to have autonomy to secure that death, is shaped by the metaphysical and metaethical assumptions of the humanist moral background. Although care work exposed participants to the circumstances of dying, the way that they applied the autonomy principle to those circumstances was structured by the



assumptions behind the autonomy principle. The idea that one can have control over the timing of death rests on a number of assumptions about life, death and time. It assumes, for example, that one's death is not a product of fate, but rather, is a product of circumstance, chance or will. Consequently, participants in the movement hesitated to delegate the authority of determining the timing of death to either professionals, or to a divine entity. Rather, they sought to bring the timing of death within their own control, avoiding entering "vegetative" states, losing their dignity, or otherwise losing control of the capacity to determine the timing of their deaths.

## 9: EXPERIENCING DEATH II: AUTONOMY AND IDENTITY

In this chapter, I continue the discussion about the timing of death. Given that participants were concerned with being in control of the timing of deaths, it is also possible to examine the reasons why timing itself is important to participants. The main concern of the participants in the study was to end their lives while they were still able to maintain their identities. Over the course of doing care work, participants were frequently exposed to situations where the people for which they were caring lost physical and cognitive capacities. These impairments hindered identity work, and raised questions about the identity of the dying person.

### *Autonomy, Identity and the Good Death*

Autonomy is important to people involved in the pro-euthanasia movement because it is tied to the capacity of maintaining their identities as they die. The final life project, or death project, is centred on the good death, which entails a maintenance of identity in the face of physical, cognitive and social decline. The development of identity in the time between when one is aware that one will die in the foreseeable future and when death occurs, is the primary goal in dying well.

The death project is a reaction to changes in how death due to ageing or illness is organized in modernity. In his influential history of death, French historian Phillipe Ariès (1977) details the important role of the deathbed in medieval Europe, as a space for taking stock of one's life. In Ariès' view, the deathbed was the best opportunity to do this. Depictions of the deathbed in medieval Europe often featured an angel or other representation of God witnessing the dying person's last moments. For Ariès, these depictions symbolize the importance of the dying space and time: it gave people a chance to settle debts, come to terms with their lives, and ultimately prepare to leave the world (Ariès 1977:35-41). Ariès argument is essentially that with

the onset of modernity, death became taboo, relegated to the private sphere, handled by professional medicine, and essentially dis-embedded from its traditional social surroundings. With this movement, the chance for the person to assess the meaning of the lived life was minimized (Ariès 1977).<sup>48</sup>

The space for death projects on the deathbed was minimized not only by changes in social norms in modernity, but additionally, and perhaps more fundamentally, advances in medical technology. The experience of doing care work is itself mediated by another intervening condition: the prolonged nature of death in modernity, and the consequent impact on how care for the dying is managed. That is, while the increase in the belief that people should be the governors of all aspects of their life appears to be responsible for increased support for MAiD, this relationship exists within the structural and cultural context of mortality – the ideas and practices around life and death, the division of labour, access to certain kinds of death, and ways of caring for the dying. In 1977, psychologist and eminent thanatology scholar Herman Feifel (See Woo 2003) commented on the state of modern dying:

It is obvious that problems concerning the dying patient are much more center-stage these days than they used to be. A seminal reason for this, I think, is the advances taking place in medical technology with their marked impact on the process of dying. We are altering the character and duration of dying, and the diseases we die from. In the old days, we died from acute and infectious diseases, e.g., pneumonia, tuberculosis; today, with the forward march of medicine, we tend to die from the more chronic and degenerative diseases, i.e., those associated with heart, cancer, and stroke. The prolongation of dying these days has also aggravated the problem of personal dignity and control for the seriously ill and dying person, and exacerbated such problems as loss of self-esteem, pain, depression, and dehumanization. (Feifel 1977:10)

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<sup>48</sup> Although one can disagree with specific aspects of Ariès' account (the timing, the degree to which death is still taboo), he reveals an important dimension of death; dying is an interpersonal, interactive process that relates fundamentally to human selfhood.

Feifel raises a point that sociologists have echoed (Howarth 2007a): the changing timing and conditions of death have altered the set of problems caused by mortality. The fact of being more likely to die from long-term, chronic and degenerative conditions means that people are more likely to foresee the cause of their deaths well in advance. But it also means that they enter longer states of dependency, relying directly on caring others for daily activities. Over the course of this care, carers are exposed to the vicissitudes of mortality, which later becomes part of the set of experiences they relate to while developing their own end of life plans.

The best deaths give the person a chance to undergo a final socialization, grasping finally what it means to be mortal, and accepting the lived life. In her critique of the “bad death,” physician and social analyst Marilyn Webb describes the importance of the quality of the dying process for the dying person. She notes that a “bad death” is one where suffering is so great, and its onset so sudden, that total immersion in physical and emotional distress prevents dying people from being able to come to terms with their mortality. She contrasts this with the “good death,” where the dying have adequate time, energy, and space to engage meaningfully with friends, relatives and family, coming to terms, once and for all, with who they are, and what they mean to themselves and others (Webb 1997). In the good death, people enter a final, culminating stage of identity-formation, where they incorporate death into their personal identities.

In this section, I argue that the process Webb describes is what is at stake for the people involved in the pro-euthanasia movement. Participants in my study, as well as authors of secondary documents, refer to the importance of maintaining control over how and when they die, to avoid the variety of negative circumstances that lead to a “loss of self.” (Charmaz 1991) In her study of how chronic illness impacts sense of time and self, Kathy Charmaz describes what it means to lose yourself: “Loss of self means being involuntarily dispossessed of former

attributes and sentiments that comprise one's self-concept, as well as the actions and experiences upon which they are based. It also means losing the self-definitions with which one had most identified." (Charmaz 1991:257). In this regard, what Charmaz terms "self" might be more accurately called "self-concept" or personal identity: "the concept the individual has of himself as a physical, social, and spiritual or moral being." The self, on the other hand, refers to the reflexive process through which people reflect on their lives and make their decisions (Gecas 1982:2). Self-concept is formed in relation to one's perception of one's personal characteristics, as well as the "imagined appraisals" (reflected appraisals) of others.

Self-concept and personal identity should also be distinguished from social identity, or the characteristics that people attribute to others to locate them socially. According to both realists and symbolic interactionists, people exercise agency in assembling their self-concepts and identities. Pertaining to the former, people deciding who they want to be, and committing to some features of their identities while distancing themselves from others. Thus, the loss of self Charmaz describes refers to the loss of agency – the "dispossession" of autonomy – over the fundamental realm of personal identity.

When it comes to medically assisted dying, people describe a fear at losing the aspects of themselves that make them unique – their self concepts. In this regard, autonomy – discussed in this chapter as control over the timing of death – is resonant with these participants because it will allow them to terminate their lives when it is no longer possible to maintain the self-concepts that they so closely attach to themselves. There are at least four "types" of self-concept that are at risk of becoming lost if they are unable to decide when and how to die: 1) the aesthetic self, 2) the physical self, 3) the cognitive self, and 4) the social self. These types often intertwine in the data. Nevertheless, as ideal-types, they are distinct enough to warrant individual treatment.

*The Bad Death: Losing Identity*

In her research with FATE activists, Richards found that their “self-identity was dependent on a sense of agency, which they feared would be compromised by deteriorating mental and physical capacities.” (Richards 2012:18). For the participants in my study, the loss of sense of self and identity, due to deteriorating mental and physical capacities, was important. However, the participants’ accounts of why they believe in the moral right to medically-assisted death, reveal that doing care work was one of the main ways through which they became concerned with the loss of self. Their concerns about autonomy are rooted in their experience of caring for the dying, where they confronted multiple dimensions and conceptions of self and identity: the aesthetic, the physical, and the cognitive. That is, participants wanted to have control over their lives as a pre-condition to maintaining a sense of self and a personal and social identity until death. They wanted to die as themselves, and not someone else.

*The aesthetic self*

The aesthetic self relates to the sense of oneself and others as objects of sensory pleasure and displeasure. For the participants, it was related to one’s experience of one’s own state of mind and body – more seriously, whether one is suffering or not, feeling good or bad, and so forth, as well as the quality of the death itself – good or bad – and the memories left to surviving loved ones. Again, we see the moral background shaping the way that the principle of autonomy is enacted. Instead of suffering being meaningful from the point of view of spiritual experience or medical achievement, it becomes meaningful, and perhaps negatively so, as a process comprising the aesthetic value of the good life.

One participant in the study identified herself as a “sybaritic activist,” devoted to the pursuit of pleasure in her life and in others’ lives:

(...) I say that I am sybaritic, and I am activist. (...) And it's a term from the world of the new testament. (...) Sybarites were citizens – residents of a city where they were devoted to pleasure. It's something like Hedonist. Basically, I care quite passionately about how things taste and smell and look and feel and sound, and I'm not at all embarrassed to do that. (...)

(...) In our country, the movement kind of started with the French part of the country. (...) French people have no shame at all about caring passionately about the temperature of their wine, the age of their cheese all these things, they don't feel that it's decadent or anything, they just care, they don't mind people knowing that they care. And I'm like that. There's a lot of English people, 'les moody Anglais,' they, some of them have a little bit of the Calvinistic, puritanical, streak in them, and they think that you know, cold showers, bite the bullet, et cetera, et cetera, I've never been like that, and I never will be. And so it's just all of a piece with me to care about the last part of my life and what it feels like.

For this participant, caring about the aesthetic quality of life is a fundamental part of her self-concept. It also structures her experience of the world, as she is concerned, in Archer's sense, with maximizing aesthetic pleasure and minimizing aesthetic displeasure. Her life project is oriented partly around aesthetic goals. She continues to describe how she is also concerned with how other people experience the world: "And I'm also an empathic person, I care about what other people feel like."

For this participant, the aesthetic dimensions of death are multidimensional. In the first place, a difficult death – filled with suffering – will lead to bad memories, which, aside from their emotional connotations, are also aesthetically undesirable. More directly, a death filled with suffering is "uncomfortable" and ultimately something to be fixed: "all that matters is that the situation can't be fixed to your satisfaction. And that you're life has been made miserable by it, and will continue to be made miserable by it until it ends." She explains how this aesthetic self is compromised by a bad death, one filled with suffering:

Sometimes [people] become someone they never wanted to be, and don't want to be remembered as being and so on, and people with things like Alzheimer's and so on, or just someone who's constantly moaning, and in pain makes people selfish. Suffering makes people [intake of breath] focus inwards and be selfish and be

unpleasant to visit and hard to get along with, and it's not a good, people end up dying as somebody other than themselves.

In this statement the participant connects suffering with the loss of self. There are multiple conceptions of self-concept at work here, as part of suffering relates to the physical self.

Nevertheless, the idea that people become “unpleasant and hard to get along with” reflects the idea of self devoted the pleasure, since the potential pleasure of the mere presence of others during dying is tainted by the loss of the ability to govern oneself. In the bad death, pain deprives dying people, and those around them, with the chance at finding any pleasure in the development of bonds with others. In this regard, suffering compromises identity on a number of levels. On the first place, it negates the capacity of the person to enjoy his or her life. Secondly, it negates the meaning of that life to other – the social identity – removing the pleasure not only of living life, but of recalling and experience a person with whom one is close.

Consequently, the painful death also deprives relatives and friends of good memories of the dying person:

Terrible things, terrible memories are given to surviving relatives and friends of people who have horrible deaths. (long pause). I still regret some of the things I did and didn't do when my husband was dying, and my mother, those are the two closest people to me who died. And it's not better, because it wasn't really terrible, but some people have terrible, terrible memories and self blame and so forth and so on, if it's a badly managed death.

Another participant echoes this sentiment: “I don't know if you've watched somebody die, but it was awful. It made all of our memories like, I didn't even recognize. I could barely recognize him and I had seen him three weeks or four weeks before.” There is a desire to control death not only so that it will be comfortable, but also so that “good memories” of the person will be preserved. Again, yet another participant expresses the same view: “But it's really hard for the love ones to have to watch that because they suffer too. Then they have harsher memories and



things like that. Like I find myself, whenever his face comes to mind, is I pull back an earlier memory when he didn't look so awful, (...)." These memories also have ramifications for the social self, since they allow the person to extend a self even after death, knowing that they will "live on" in the minds of others.

One participant is particularly candid about the aesthetic dimensions of mortality, which he connects to his grandfather's decline, and interestingly, the physical self concept. Describing ageing, the participant told me the following:

I mean, even with me, I mean, balding's not a big issue but I see old age kicking in. I mean, I'm starting to bald, my hair's thinning, it's turning white. The sagging skin. Like, it's ... not that this is a big issue, but to me it's ugly. Like, when I see old people, it's just, it's ugly. Like you see someone hunched over, it's just an ugly ... it's not attractive, that's for sure.

For this participant, ageing is aesthetically undesirable, and something to be avoided. This participant was exposed for the first time to the aesthetic dimensions of ageing when, as a teenager, he shared a family home with his ageing grandfather. The participant's view of his grandfather's decline, especially regarding his grandfather's physical strength, and how it relates to the participant's own self-concept, reveals the links between aesthetic self-concept, autonomy and physical self concept.

### *The physical self*

There are aspects of self-concept that relate to one's physical capacities: the ability to move and interact physically with objects. For the participants in my study, their time caring for others exposed them to the ways that losing physical capacity can undermine a person's identity, both to the person experiencing the loss of capacity, and the people who witness it. For the person who loses capacity, changes in physical capacity compel the person to abandon habitual ways of judging themselves – expectations, plans and standards for performance must be altered

(Charmaz 1991:21). For the people witnessing the loss of physical capacity, that loss alters social identity, insofar as it undermines perceived characteristics, which make the person “who she is” in the eyes of others.

Returning to the participant who lived with his grandfather, we see how the loss of physical capacity changed the view the participant had of his grandfather. The account is lengthy, but is worth quoting in detail:

I saw my grandfather, my grandfather who lived up north, came to live with us in the house as got older. And I saw, he was a strong man. Like when he was younger, he used to work as a mechanic and he would always shake our hands as a joke and like, in his prime, he could literally take someone's hand and crush it. Like, he had man hands. Like, he had thick fingers and just like strong hands.

And he was strong. I mean, he did farming up north. He was a strong man. Like, just, you know, he didn't exercise in terms of weights, but he was a strong dude. But as he got older, he ... well, first old age was kicking in, I mean, and he just got slower. But he had this, I don't know if it was a cyst or something on his leg that had to be operated on, and that set him back. Like, that operation, he was bed-ridden for a while and then he started deteriorating. So he had to come live with us.

And I saw him deteriorate slowly, from someone who was, you know, he was this strong guy. And he, the ironic thing was, I mean he could barely walk, well, near the end he couldn't walk, but his hand, he still, even though he didn't exercise, he still had that like, gorilla-style ... That's one thing, even to the day he died, he could still like, he just had that clamp. So he was strong in that sense. But I saw him slowly deteriorate where at first he came over and he could walk around. And then at first, he could go downstairs and he would shower, but he was slow, you know? He would cook a little. And he just slowly deteriorated.

And he, well, he lived in the living room, so he would watch TV all the time. And then eventually it got to the point where he had to urinate in one of those like jugs and we couldn't really take care of him to that extent. So someone came in and watched him Monday to Friday. And then he moved into an old age home, he's Ukrainian, he moved into a Ukrainian old age home just down the street from us. So luckily it was like a two minute drive. And he stayed there for about, I think two and a half years and then he passed away. But just, you know, bed-ridden and got worse and worse and you know, passed away.

In this account, the participant emphasizes his grandfather's physicality and strength. The loss of that strength signalled a loss personhood, something to be avoided in the participant's own life:

“Well, that showed me, that really solidified, 'this isn't a good life'. So like, I mean, watching him

deteriorate ... the first thing like at that time, it's like, "I'm going to start exercising because I never want to end up like that." (...) that really emphasized to me that, I told my parents too, it's like, "There's no way I'm ending up like this."

Another participant describes a similar phenomenon, albeit related to a mechanical skill, rather than physical strength. She describes the importance of playing piano to her grandmother, and how, through rheumatoid arthritis, she was stripped of this important part of her self-concept:

Her knuckles on her hands were all swollen, and I can remember when I was a kid and taking piano lessons, she told me she used to play the piano, and I didn't even know that. I can remember her holding up her hands and saying 'well look at my hands. They won't let me anymore.' (...) And so I think the hard part for me isn't the death. It's the deterioration. It's seeing somebody that's close to you become ill and suffer and decline and not being able to be who they were, you know?

For this participant and her grandmother, music is a central part of social identity (the participant also mentions that playing piano and music were important to her own mother). Playing piano was an activity they shared, and established a sense of who they were to each other.

In this case, the loss of physical capacities engenders a twofold loss of self. Directly, the person's self-concept -- internal to herself -- is compromised, as an activity with which she identified was no longer feasible. Indirectly, the loss of physical capacities compromises the person's capacity to participate in an activity that is shared with others, which in turn compromises her social status as a "doer" of that activity. Another participant describes how her husband's cancer changed him. She describes him as an active man, whose physical and mental decline deprived him of the ability to be himself:

[my husband] lost his dignity. He was no longer the man of the house, the father, and the husband, and the provider. We were back in the generation where there were far more traditional families where I was very happy to be at home and make a home for my family and he was very happy to support that family financially. He lost that. He was thin, and frail, and weak, and couldn't think straight, and

couldn't move well. So, he lost his dignity and there's nothing you could do to give it back.

The participant recounted how her husband felt about these changes: "He did say that he felt so lonely. I would say to him, 'You have me, you have us. Don't feel lonely.' He said, 'I know that, but it's just this thing separates me from everybody else and makes me feel alone.'" Once the decline in mental and physical capacities deprives the person of other aspects of self-concept, he is left with illness, which becomes a kind of master identity in his self concept.

She also describes how her children experienced their father's change of identity: "They, of course, had to watch their father who had been extremely fit and very active and a very good, and devoted father, doing lots of sports and fun things with everyone. All of us. And coaching their hockey and soccer and so on and so forth. They watched him go down to about 80 pounds and age 30 years. He looked like he was an old man of 90." Their father's illness, and the reduction of his physical capacities, flipped his social status, turning him in to the receiver, rather than provider of care: "My youngest son, who was eleven, twelve, thirteen during that time, he was so amazing with him. He would sort of say, 'Come on, Dad. You've got to come and sit here.' Or, 'You can't do that, Dad, because [his father] was so confused.'"

### *The cognitive self*

In addition to aesthetic and physical aspects of the self concept, there are also the basic, cognitive capacity that for most people is necessary to maintain self-identity. In the first place, basic cognitive capacities make it possible to have an internal conversation, to reflect on oneself and the world, ordering things into a coherent biography that can be shared with others. When this is ruptured, that biography and identity is compromised. Furthermore, for some people, cognitive capacities themselves – that is, the capacity to be reasonable, to communicate well, and to think – are part of the substantive contents of their identity. In a polemic in favour of

recognizing “prospective autonomy” (the weighting of advanced directives in favour of the autonomy of the pre-dementia, rather than post-dementia patient), legal scholar Norman Cantor writes the following:

This wish to hasten my post-competence demise is not based on prospective suffering or distress, but rather on my personal vision of intolerable indignity and degradation associated with cognitive dysfunction. For me, it is critical to shape the post-mortem recollections of my loved ones and to preserve the lifetime image as a vital, critically thinking individual that I have strived to cultivate.

For Cantor, his cognitive capacities, his identity as a “vital, critically thinking individual,” are part of his self identity.

In the pro-MAiD movement, the loss of cognitive capacities is primarily related to dementia. Participants in my study tended to describe the process of cognitive decline as Cantor does; compromising both their ability to maintain identity, and compromising identities based on intellectual capacities. One participant talked about her mother’s ten-year decline with dementia, and how it first came to her attention when her father let her know that her mother’s spending habits had changed:

So my dad, I guess he called me first. Anyway, so he said his initial complaint was I'm worried about your mother, and so we said well what's the matter, well he says I'm really having a struggle, I think she's slipping, and he said I'm having trouble handling it. Well what's the matter, well okay, so the big issue that he was really stewing and fretting about was money. He said she's getting all this crap in the mail, and she's signing up for everything, and she's donating to all kinds of crap, and I'm trying to monitor the mail, and I'm trying to stop it, and she argues with me, and she gets upset, and she's not reasonable.

The participant notes that her mother’s habit of signing up for things in the mail represented a change in her personality, from a critical thinker to a potential target of scams:

He says I think her mind is slipping. So we said we would help him handle it, and he started bringing this tons of mail. Well it was very clear that my mother was obviously in the early stages of dementia. My mother was smart. She was a legal secretary for years. She was a critical thinker. Both my parents were very big on

don't fall for bullshit scams, and you know, there's a sucker born every minute. This is not something my mother would have done if you know what I'm talking about earlier.

Later in the progression of dementia, the participant moved her mother into a long-term care facility. By this point, the decline in cognitive capacities had compromised her mother's basic life activities:

For some time, she was happy in her wandering dementia, not knowing where she was state. For the first couple years that she was in a personal care home, and she began to deteriorate more, and she stopped walking, and she stopped feeding herself. By this time, it would have been 2011, 2012, and there was no physical reason for her not to do those things, except the deterioration in her brain was just ... Her brain was just forgetting what to do and how to do it. You would put a plate of food in front of her, and she would just stare at it. You would have to pick up a spoon and say here. The same as like if she was sitting in a chair, you'd say to her, stand up, (...), but she would just sit there and look at you, deer in the headlights. It was like her brain wasn't processing.

Near the end of the progression of dementia, the participant's mother could no longer recognize family members:

My son and daughter-in-law had their second baby in April of 2012, and when we took that baby up, we got no response. So just in that year and a half, that's how much she went down. She didn't even smile at the baby. We couldn't even get her to look. We couldn't get her to focus. Look, Grandma, we have a new baby. She didn't even focus. We couldn't hardly get a baby picture with the family. We did manage. We got a photographer, we wanted to get a family picture, you know what I mean?

(...) Basically from (...) maybe the last three, four years of her life, (...), when our first granddaughter was born, she had enough quality of life, she would still listen to music. She still recognized oh that's a sweet baby. By 2012, she didn't. I would say probably the last three years, she didn't recognize anybody in her family. She didn't really respond to anything, not music, not faces, not food. What a life.

For this patient's mother, her personality, her ability to interact with others, and even her ability to complete simple daily tasks relied on her cognitive abilities. With these in decline, her ability to participate in social life evaporated.

### *The loss of social identity*

The cumulative effect of losses in aesthetic, physical and cognitive capacities is not only the loss of sense of self, but additionally, and perhaps more devastatingly for family friends, the loss of social identity. Indeed, the participant mentioned above contrasts her mother's bad death, with her father's relatively "good" death, where:

He had his marbles right up to the very last week before he died. As a matter of fact, the week before he died, the home care attendant took him downstairs to the cribbage game, and he won. He was alert, and he was with it enough. It was only his body that failed. He was totally with it enough to worry about what was going to happen, but he never had pain. He just sort of became weaker and weaker and stopped eating and just faded out.

Although her father's death was still difficult for the participant, she notes he was able to participate in social activities and maintained his sense of self up until death, largely because his cognitive capacities were intact. Another participant talks about how, although her father was unconscious, his deathbed became a place to reconstruct his identity through stories and reminiscence: "Then on the last day, there was two brothers and myself and my step mom and I was the only one who could sit at my dad's bedside and hold his hand. The other ones had a really tough time with that. But the four of us sat within like five feet of dad and we looked at photo albums and shared stories and laughed like for five hours straight that day." The good death in this case is one where the social identity of the person is maintained.

Thus, one of the most pervasive fears for participants in the study was the possibility of losing their social identity, because of the decline in aesthetic, physical and cognitive capacities. The loss of social identity encompassed three elements: 1) loss of social status, 2) loss of socially-recognized personality characteristics, and 3) loss of the capacity for social interaction within social norms. In the interviews, participants referred to changes in social status, as well as

the loss of personality characteristics that made people “who they were,” as elements of the self that were at risk of being lost through the bad death.

Starting with personality, one of the fears that surfaced in the data was gaining a set of emotions that were not truly one’s own, and thus, contradicted the reflective self. Interestingly, in one case, these two aspects of the self-concept – the status and reflective – presented themselves together. In a newsletter sent out to members of an Ontario RtD group, the author relates an anecdote about the emotional changes that overcame a relative who was suffering from dementia:

One of my uncles was a brilliant university professor and a gentle person whose hobby was painting landscapes, but he developed dementia and became subject to rages so extreme that he had to be institutionalized. In one of these rages he tried to push a little old lady through a plate glass window. (Presumably his sedation level was immediately adjusted upwards.) His son, a cousin with whom I was quite close when I was a child, is having his prime-of-life years blighted by the fear of being similarly betrayed by his nervous system. Many other Canadians, with or without a genetic connection to a dementia victim, are equally anxious.

The anecdote presented in the newsletter reflects fears of losing social status, losing personality characteristics with which one is associated, and finally, losing the capacity to interact with others in an appropriate manner. Consequently, for someone who is recognized first as a competent professional and a “gentle soul,” flying into fits of violent rage undermines both self-concepts, as well as removes the ability to interact politely with others.

The loss of social status resulting from physical and mental decline are often intertwined with the loss of the “physical” self-concept, as discussed in the previous section. Nevertheless, sometimes declines in physical capacity lead to a loss of self that stems not from the conception one has about one’s physical capacities, but rather, stems from the inability, due to cognitive and physical impairment, to fulfill the requirements of social roles. Coming back to the case of the participant whose husband lost his physical sense of self as he deteriorated due to cancer, his



physical impairment also prevented him from easily fulfilling the requirements of his professional role:

I do remember, [my husband] worked with Shell Oil, and they were absolutely wonderful to him. They would come in, even when he was in Intensive Care, they would come to see him. Others might think, well that's rather odd, but they'd actually come and talk to him about work stuff and say, "Oh, we were wondering what you thought about that." And so on. They were giving him back his dignity. They were making him feel valued. (...)I know once he managed to come through the worst, and we got him at home, every so often I would take him [to the refinery] and they would come down and two of them would carry him ... You know, put their arms across so he could sit on their arm, they would carry him up to the offices and let him spend some time there. I would just go into the cafeteria and read a book and have a cup of tea, just so he would be part of his life and use his brain and so on. I really appreciated them for that.

This participant's husband's cancer prevented him from participating fully in his professional role. Nevertheless, periods where the illness was not as pronounced allowed him to temporarily move from the sick role (Parsons 1991) back to his professional role.

The sense, among advocates of medically-assisted death, is that the better death involves maintaining a social identity even in the face of cognitive and physical impairment. In a personal account posted on Dying with Dignity Canada's website, Barbara Sutherland discusses her father's time in the veteran's hospital at Sunnybrook, and his eventual decision to have his pacemaker removed. She notes his physical and cognitive impairment:

From February 2014 to the spring of 2015, my father's cognitive functions were in steep decline. Confusion and forgetfulness were engulfing him. It had been well over a year since my father attempted to read anything. He had been a passionate reader. The TV was turned on by the nurses to keep him company. Speech was becoming an issue. Occasionally he would manage to make a phone call when he really had something to say.

Nevertheless, she emphasizes her father's autonomy and agency in this process, noting his maintenance of social identity:

In May 2015, the doctor had more conversations with dad, always addressing him as Dr. Sutherland. Again, his wishes were revisited. The entire care team assured us

that my father's wishes were to deactivate the device, thus returning his heart to its natural rhythm. Dad said, "Although I am thankful for having had the pacemaker, I don't want it anymore." And so he chose to discontinue a treatment that would've kept him alive with an ever decreasing quality of existence.

My father, though severely forgetful, was still well able to grasp a situation and process it, in the moment. My husband went in to see dad on the designated day to make certain that his mind was clear and that he didn't want to change it. He left satisfied that dad was being guided by his own principles. Dr. Sutherland was taking back the "helm of his ship". As a sailor, he loved this analogy.

In this account, which is framed as support for the idea of autonomy in the dying process, we see that Dr. Sutherland's death is deemed a dignified one, since he was able to remain himself, and in control over his circumstances, even in a state of cognitive and physical impairment. He retains his social status (being addressed as "Doctor"), his personality traits (a strong sense of agency, appreciation for sailing), and retains the capacity to interact meaningfully with others around the issue of his death, within the framework of social norms and propriety (his conversations with psychiatrists, nurses and physicians about the physical and emotional ramifications of having the pacemaker removed). In this sense, Dr. Sutherland's death is the antithesis of the bad death, since he had the time and capacity to maintain his sense of self and social identity until his death.

### *Conclusion*

The participant accounts presented in this chapter demonstrate that the main concern around a prolonged or early death is the inability to main one's identity. Dying is an important time for a person to come to final terms with the lived live, and curate the image of themselves they wish to leave with others. Physical and cognitive decline, as well as intense suffering, compromise personal identity on a number of levels. First and foremost, suffering corrupts the person, taking over their senses and time, and leaving them with few resources to come to terms with death. This suffering also corrupts the memories others have of the dying person; the image

of the dying body, or even the dead body, comes, at least for a time, to dominate all memories. Physical and cognitive decline, on the other hand, compromise the ability of the person to participate in the activities with which they identify themselves and other identify them. In sum, these multiple deteriorations diminish the capacity to maintain a desired social identity. This fate, of losing identity, is what members of the pro-MAiD movement seek to avoid by asserting their right to control the end of their lives.

## 10: CONCLUSION

### *Research Question and Findings*

The purpose of the dissertation study was to investigate the ways that pro-MAiD belief is shaped by the experiences people have had with death and dying. How has the experience of caregiving, bereavement and/or serious illness shaped the issue of euthanasia for volunteers and other actors involved with pro-euthanasia organizations? The primary theoretical conclusion of the study is that over the course of caring for dying people, pro-MAiD persons developed a propensity to believe in the principle of autonomy – dying people should be in control of their own deaths. This propensity was shaped, along with the act of caring, by the humanist moral background of the identities of the participants in the study.

In Chapter 2, I discussed the historical context of autonomy in the pro-MAiD movement. On June 19th, 2016 the Criminal Code was changed to allow for medically-assisted death. Yet, this legal change happened in the context of three main historical forces: 1) the secularization/decriminalization of suicide, 2) the development of the hospice and palliative care movements and 3) public coverage of MAiD cases in the United States and Canada.

In Chapter 3, I presented the theoretical frame through which I approached the research. The frame is centred on critical realism and social psychology. I used critical realism to conceptualize social change, and to explain how individual agency contributes to effecting social change. Fundamentally, the legalization of MAiD represents social change in a multiple domains – from the legal, to the normative, to the agential. Autonomy, as we have discussed, played a key role in this change, as one of the key organizing principles of the pro-MAiD movement. Yet, ultimately, social change happens because the life projects of agents line up with structural and cultural conditions. Acting on the basis of self-defined priorities and situationally

incumbent logics of action, individuals negotiate cultural and structural conditions throughout their lives.

One of the principle contributions of the theoretical frame is to use the CR conception of agency and social change to develop a conception of morals and morality. I defined morals as normative cultural principles. Morality refers to the ways that morals are applied to social context and concrete situations, histories and events in the lives of individuals. In this regard, I conceptualize morality as a kind of moral identity. Based on this conceptualization, pro-MAiD is an identity that integrates and applies the principle of autonomy to the realm of death. Because it is a cultural principle, autonomy brings with it its own situational logics that place constraints on individual action. Once an individual accepts the autonomy principle, her potential life projects are shaped by autonomy.

A key distinction of the theoretical frame was between thin and thick moral concepts. Autonomy is a thick moral concept, in that to be meaningful it depends on social context – the moral background specifies aspects of autonomy, including the range and limits of how it can be applied. According to Gabriel Abend's conception of the moral background, it includes six elements: metaphysical and metaethical assumptions, grounding, method of argument, conceptual repertoires, and objects of evaluation. Integrating the moral background into CR, we can see these elements as coming into effect at the socio-cultural level, shaping the ways that autonomy is applied by individuals in concrete situations.

According to the theoretical frame, the participants in this study are primary agents, while organizations like Dying with Dignity are corporate agents – collective entities that translate and represent the positional or vested interests of primary agents. In terms of the principle of autonomy, it is taken up by primary agents in regard to MAiD within a humanist moral

background. This humanist moral background then comes to inform the positions of corporate agents as they take up primary agent concerns. The primary question motivating the dissertation research, then, was: how is the pro-MAiD identity informed by experiences of death and bereavement? Again, this was primarily a question of how a specific set of life experiences – death and bereavement – were interfaced with the principle of autonomy in the pro-MAiD identity.

In Chapter 5, I began to answer this question, and started with autonomy as a cultural principle, discussing its prominence in the pro-MAiD movement, and the humanist moral background of the principle. I discussed how autonomy is central to pro-MAiD identities, in particular discussing its presence in corporate agent statements, participant reports, as well as its codification in medical ethical frameworks. Most importantly, however, I introduced the idea that humanism shapes the way that people understand autonomy, and the way that they apply it to their life experiences, especially around death, bereavement and care.

In terms of the moral background, participants discussed being socialized into broadly humanist views in a variety of ways: some were introduced to humanist ideas by their parents, others discovered humanist publications on their own. Regardless, the human moral background shaped the ways that participants thought about autonomy. In the first place, it set their metaethical and metaphysical assumptions. Primarily, the participants saw the universe as subject to mechanical forces, but devoid of intrinsic spiritual or moral meaning. These metaphysical and metaethical assumptions led to the grounding, which, recalling the discussion in Chapter 3, refers to the justification for being moral. The participants tended to believe that it was “better to be good than to be bad.” This tautology emerged from the moral neutrality of the universe. Given the absence of intrinsic moral meaning, good things were not granted – they

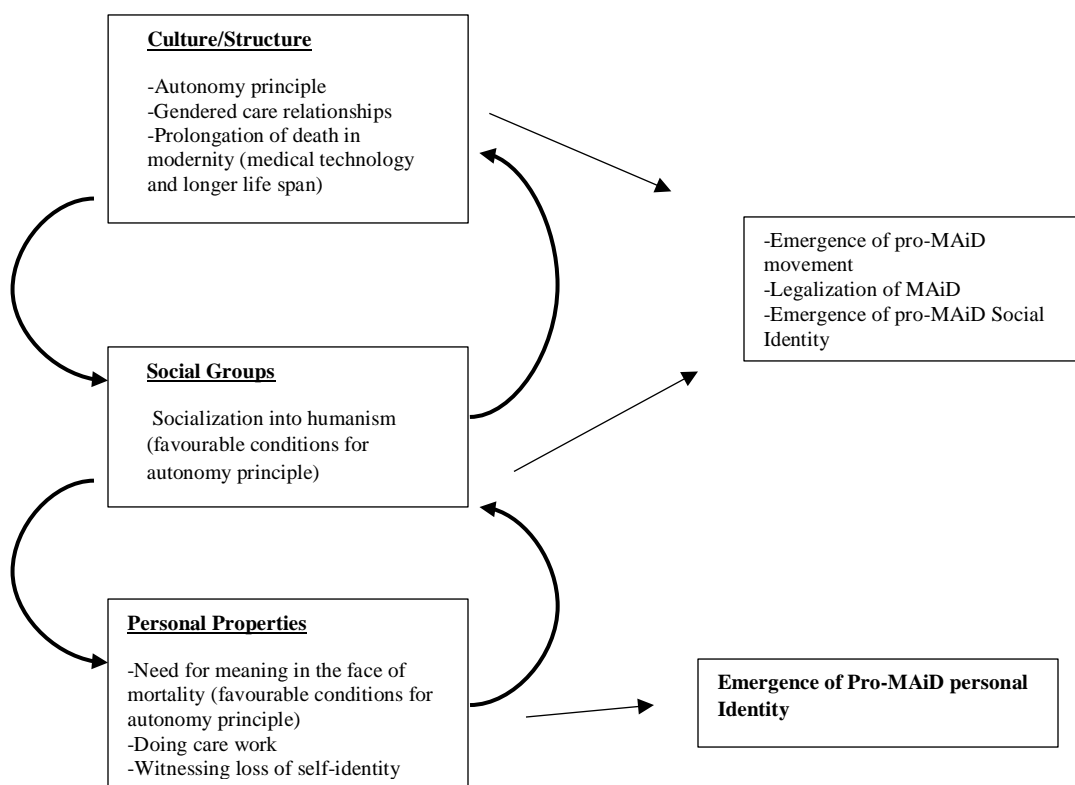
were not assumed to “just happen.” Consequently, participants believed they had a duty to further good, because there was no supreme being to do so. In terms of “method of argument” or moral epistemology, the humanist moral background includes a scientific epistemology where moral decisions are to be made on the basis of evidence, including the evidence of subjective experience. Humanist conceptual repertoires and objects of evaluation included the ideas that suffering had no intrinsic moral meaning, and was thus a domain that could fall under the purview of autonomy: humans should be able to exercise autonomy in the face of their own suffering, since there is no inherent reason to suffer.

Chapter 7 was focused on looking at how the principle of autonomy, deployed in the pro-MAiD moral identity, comes into effect by way of another intervening condition: doing care work. Although the way that participants made sense of autonomy was shaped by their exposure to humanism, autonomy had to become relevant – or align with – the specific life projects of participants to become causally efficacious. In this regard, the principle of autonomy had to resonate with the concerns of participants. In Chapter 8, I argue that autonomy was relevant to participants over the course of their time doing care work. This care work was both formal (paid) and informal (unpaid), and covered both affective and instrumental care. While caring for family members, friends, and even complete strangers, carers empathized and sympathized, developing a strong orientation to the well-being of the people for whom they cared. Due to this bond, the carers expressed the sentiment of not wanting to “end up” like the people for whom they were caring, especially when it came to dying too early, or dying over a prolonged period of time.

In Chapter 9, I further discussed the fears of the early or late death, and linked them more specifically to fears about the loss of identities. While caring for others, carers witnessed those others lose various aspects of their personal identities – what I call aesthetic, physical and

cognitive dimensions of the self – that comprised their ability to maintain social identities. In essence, carers witnessed patients lose their personhood. They believed autonomy was important, because it would allow them to determine the time of their own deaths, and thus avoid the loss of control over self that is so key to the maintenance of personal identity.

The diagram below shows the grounded theoretical explanation produced in the dissertation:



### *Research Limitations*

### *Theoretical Findings and Representativeness*

Although the dissertation study produced some important findings, it had important limitations. In the first place, it should be emphasized that the findings presented here are



*theoretical*. The purpose of grounded theory is to produce workable theories, not empirical conclusions. Thus, while the findings give us a glimpse into the working of the pro-MAiD movement, the causal relationships proposed here – between the humanist moral background, the experience doing care work, and the principle of autonomy applied to pro-MAiD belief – are theoretical and must be confirmed by quantitative study using representative samples. The research design developed for the study was relatively focused on vocal, highly engaged, highly educated and highly active members of the pro-MAiD movement. Future studies would have to find a way to incorporate the voices of more marginal members of the MAiD movement – perhaps they would have different stories to tell. Consequently, these findings should not be taken as empirical findings to be generalized uncritically to other settings, but rather, as a preliminary theory to be tested.

#### *Researcher subjectivity*

While I endeavoured, through careful coding and research journaling, to suspend my own pre-suppositions while approaching the data, my personal subjectivity no doubt entered into the analysis. On the one hand, this is a necessary part of grounded theory, since developing theoretical sensitivity requires drawing on one's own experiences, as well as disciplinary knowledge. On the other hand, personal experiences can sometimes skew data analysis and predispose the researcher to follow personally resonant leads over ones that are not as personally resonant but are nevertheless theoretically important. Further research will have to be conducted to confirm the importance of the autonomy principle, especially in the context of care work. My own experience of caring for a dying loved one could have impacted the way that I constructed the theoretical concepts, so this should be kept in mind while extending these concepts to further work.

### *Retrospective Data*

The method used in the study was retrospective. Although life changes were not necessarily the focus of the study, some of the concepts developed in the analysis, for example the idea of socialization into humanism, rely on retrospective accounts of the past by participants. It is difficult to establish, using a retrospective method, how participants felt or thought at the time that past events occurred. Furthermore, the actual occurrence of empirical events is difficult to establish, since the method relies solely on participant accounts. For another example, participants were often asked whether people under their care expressed wishes to access medical assistance in dying. In some cases, participants found it difficult to remember, and resorted to expressions like “I imagine...” or “It was likely that...”. Such expressions betray some uncertainty on the participants’ part about their own life events. Thus, although the study was focused on the pro-MAiD identities participants construct in the present, it did make some use of retrospective data.

### *Pro-MAiD only*

One of the other limitations of the study was that it focused solely on pro-MAiD beliefs, without engaging empirically with anti-MAiD belief. The choice to focus on pro-MAiD was conscious: given the increased support for MAiD, it was logical to focus on understanding this support directly by taking it as the object of study. Nevertheless, there is much to be gained by pairing the study here with a sustained examination of anti-MAiD beliefs. Although scope and resource limitations precluded such an examination in this study, an analysis of anti-MAiD identities would allow for a more contextualized understanding of the key theoretical concepts constructed in the study, chiefly autonomy. It would be interesting and theoretically useful to

investigate how the concept of autonomy is treated among people who consider themselves anti-MAiD.

### *Research Contributions*

The theory discussed in the preceding chapters is an important contribution to the sociological understanding of medically-assisted death, and perhaps, issues related more broadly to autonomy, modernity, the self and death and dying. In the literature review chapter, I began to discuss some of these contributions, but we can cover them further now, having discussed the grounded theory.

### *New Independent Variables*

In the first place, the theory presented in this dissertation introduces a number of new independent variables into the study of euthanasia attitudes, variables that could be used in further, quantitative research:

- 1) Gender and care experiences
- 2) Education and humanism

### *Gender and Care Experiences*

The research question of the dissertation was directed specifically to how death and experiences impacted MAiD attitudes for the individuals in the study. The study findings, however, show that the experience of care underlies the relationship between death experiences and MAiD. Individuals orient themselves to MAiD, at least to pro-MAiD, in terms of the care that they have provided for dying people over the life course. In terms of morality, this reveals that moral views are not arrived at through a process of abstract, deductive reasoning, but instead

are rooted in the lived experiences of people who profess those moral views. When it comes to MAiD and euthanasia attitudes more broadly, having had the experience of caring for a dying person seems to be an important determinant of subsequent MAiD views. Future quantitative work should acknowledge this finding, and incorporate experiences caring for the dying as an independent variable.

Furthermore, there is a potential conditional relationship between experiences caring for the dying and gender. Based on the extensive literature on gender and care (mentioned briefly in the literature review section), and the stories of participants in this study, we would also expect that women would be more directly involved in the care of dying people, and potentially, more engaged in affective, rather than instrumental care, especially in informal care. This causal relationship also deserves more attention in quantitative studies of euthanasia attitudes.

### *Education and Humanism*

Another independent variable revealed by this study is the humanist moral background. Although religion has been incorporated extensively into studies of euthanasia attitudes, the accounts of participants in the study demonstrate that fundamental conceptions about the universe and about what it means to be moral (metaethical and metaphysical assumptions) lie at the heart of pro-MAiD moral identity. These findings even raise the possibility of going beyond the religion/atheism dichotomy to capture the more fundamental cognitive structure of pro-euthanasia beliefs – they rely on a particular conception of the universe and of ethical action that could prevail even in situations where people identify as religious – Catholic for example – but in fact hold metaethical and metaphysical views that bring them closer to humanism than religion. What I am suggesting here is that the focus on adherence to institutionalized religion in

euthanasia attitude research is misplaced – the focus should be on metaphysical and metaethical views.

There is also a question of education. Given that humanism places a strong emphasis on scientific epistemology, it stands to reason that exposure to this epistemology, whether through formal or informal education, is a potential causal variable in euthanasia attitudes. Although some research in this vein has been done, the presence of humanism sheds light on the relationship between education and pro-euthanasia, perhaps explaining why the two might be correlated.

#### *(Dis)enchantment and the Sequestration of Death*

That participants in this study were distrustful of how Christianity and modern medicine views death reveals the fundamentally critical nature of the pro-MAiD view. In the humanist moral background, suffering has no inherent meaning. Participants in the study referred to both religious and classical medical views of suffering, where suffering was acceptable as a divine experience or in the service of “cure,” respectively. The humanist view of suffering is largely opposed to these views, and instead takes suffering as a fact of life that becomes meaningless once the sufferer is no longer willing to endure it. The pro-MAiD morality, in this regard, is firmly rooted in a critique of Christian views towards suffering and the instrumental rationality of modern medicine, both of which are seen as denying the humanity of the dying person. Neither seeking a return to a religious or spiritual enchantment of death, nor seeking to cede death over to medicine, pro-MAiDers take a sober view towards death.

This view towards death raises important questions about the broader moral texture of society, especially regarding the sequestration of death and the capacity of society to manage it. The MAiD movement, especially in its insistence on bringing death into the realm of moral

decision making, represents a movement of death out of the realm of sequestration, since it means bringing death under the governance of ethical rules. Yet, these rules themselves are grounded by humanist ideas about personal autonomy, which suggests an individualization of death. Given this paradox, further theoretical work needs to be done on the idea of the sequestration, since the case of MAiD presents a problem: a case where an object is simultaneously de-sequestered, yet relatively private, based on personal autonomy and management.

### *Ethical Reflections*

Aside from providing a theory of MAiD belief to be tested empirically, the other purpose of the study presented here was to begin to understand the social causes of the MAiD debate. This study is not a bioethics piece; nevertheless, the findings reveal two important ethical problems surrounding MAiD.

The first ethical problem relates to the perception carers have of people in their care. The findings of this study are based on first hand accounts carers have of their reactions to the situations of the people for whom they are caring. The findings are not based on first hand accounts of people near death. Thus, one wonders the degree to which the perception of dying people is biased by the humanist worldview discussed in earlier chapters. Simply put, did the carers perceive a loss of identity because they were overly concerned with an autonomy-based identity?

This question is not just epistemological, but ethical. In an important rejoinder to the MAiD debate, liberal philosopher Ronald Dworkin (1986) argues for what is now known as “prospective autonomy” (Cantor 1992) or the idea that the competent self’s wishes should take precedence over the desires of the incompetent self. Prospective underlies the push for the

recognition of advance directives, primarily in dementia cases. The assumption relies here on the fact that people suffering from dementia cannot have identities. Yet, perhaps more consideration of the dementia identity itself needs to be undertaken before the ethical problem of prospective autonomy is resolved.

This first ethical problem raises another; is the humanist conception of autonomy too focused on the individual, without recognizing the relational nature of autonomy? In my conversations with people in the pro-MAiD movement, there was some recognition that ethical decisions in humanism are socially embedded. That is, the pros and cons of any decision must incorporate the ways that that decision affects everyone around the decision-maker, not just the decision-maker themselves. Hence the argument, that arose several times in the study, that unfettered access to suicide could be potentially undesirable because of the effects on the suicidal person's family. Yet, the dictum "my life, my choice" does not necessarily admit this relational nature of autonomy. Especially when a person is dependent, his or her choices are often made in conjunction with loved ones. However, the current MAiD policy intends to insulate the decision-maker from being influenced by others. But, are decisions ever really made autonomously? What does true autonomy look like? In sum, while the study here has left me personally inclined to be in favour of MAiD, there are important ethical aporias around autonomy that will continue to persist, as they reflect the way autonomy is conceptualized and codified in modern law and society.

*Critical Realist Social Psychology: A Prototype*

In the introduction, I mentioned that this dissertation was inspired by a naturalistic or humanistic view of ethics. The reference to Erich Fromm's work in that section was neither accidental nor misplaced. Although a lengthy discussion of Fromm's opus and contributions to

social theory is beyond the scope of this conclusion, the major theoretical aim of this work was to demonstrate the utility of critical realist social theory for analyzing major and important ethical issues in our times. In his day, Fromm took up important and pressing issues, like fascism and the rise of consumerism, using a robust theoretical framework that combined Marxism and psychoanalysis. While many of Fromm's concepts are dated, the spirit of his work, namely, a humanistic social psychology that recognizes the all too human sources of our most pressing social problems, remains important.

This dissertation contributes a critical realist social psychology in that spirit. In fact, Fromm himself notes, in *Man for Himself*, the importance of what we would today call a moderate realist position in the social sciences. For Fromm, as for Archer, the central paradox of social theory is that human beings are determined and yet retain the capacity to transform themselves. This problem poses an ethical, as well as theoretical problem, which Fromm sees as manifest in the philosophy of his time (Fromm 1947, 25). Fromm points to two main ethical doctrines: 1) authoritarianism, in which ethical principles are derived from a fixed human nature (Fromm 1947, 21), and 2) progressivism, in which any ethical principle is contingent, and thus open to contestation, due to the "infinite malleability" of human nature (Fromm 1947, 21). For Fromm, neither ethical position is scientifically or morally acceptable. Scientifically, because cultural pluralism debunks the idea of a substantively fixed human nature, morally because relativism offers no concrete ethical knowledge. As an alternative to authoritarianism and progressivism, Fromm argues for a humanistic ethics rooted in the properties of humanity, which he sees as emerging from human interaction with the world (Fromm 1947:20-23). Fromm conceives of his social scientific project as a "science of man," which, due of its ability to track the adaptation of human capacities to specific social conditions, can solve the Marxian paradox and thus ground a



moderate ethics between authoritarianism and relativism. For Fromm, the problem is to develop a social theory that avoids 1) positing universal, substantive features of humanity and 2) taking humanity as “infinitely malleable” or capable of generating infinite possibilities of human being. In my view, crafting such a social theory remains an important task for social psychology, one that critical realism, as I try to show through illustration in this dissertation, is more than prepared to solve.

The primary contribution of the framework developed and operationalized in this dissertation is the demonstration that critical realism acknowledges the universal characteristics of human beings, while also allowing for the play of social construction. By analysing the interface between the principle of autonomy and the experience of death and bereavement, I aimed to reveal the ways that human universals – seen here as the need for a cohesive personal and social identity in the face of mortality, exerted their own causal power on social change. That is, by finding themselves in the position of potentially having their identities compromised in the practical order (physical self-concept) and in the discursive order (social identity), participants were compelled to adopt the autonomy principle.

Moreover, their adoption of this principle within its humanist background also structured the way that participants understood death, dying, and their own lives. In short, the principle itself also exerted its own causal power. Thus, the identities of the participants reflected the influence of three sets of causal powers: 1) the causal powers of culture, 2) the causal powers of social groups and 3) the causal powers of open universals at the level of personhood.

#### *1) The causal powers of culture*

I stated earlier in the theoretical framework that the autonomy principle, being a cultural element, exercises its own causal powers. In earlier chapters, I

demonstrated these causal powers, by showing how participants adopted the pro-MAiD identity in part because of their concern for autonomy. This exposition reveals the ways that cultural elements shape social action. It is through the adoption of the autonomy principle that the life projects of this particular group of individuals became aligned with the MAiD movement. Put in other terms, the broad project of corporate agents to legalize MAiD was only possible because constituent individuals, primary agents, shared the belief in autonomy.

*2) The causal powers of social groups*

The question arises then, if the autonomy principle is responsible for broad participation in the MAiD movement, where did belief in the autonomy principle come from? This question was at the centre of the dissertation. I reiterate the answer briefly here: support for the autonomy principle comes both from the humanist socialization of the individuals in the study, as well as from their life experiences caring for dying others. Regarding the first part of that answer, the influence of humanist socialization on support for MAiD reveals the way that the socio-cultural level, which pertains to the power of groups to socialize individuals,<sup>49</sup> also influences the outcome of social change, and enables it to happen.

*3) The causal powers of personal properties*

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<sup>49</sup> I use the term socialize here in the non-deterministic way that interactionists use it. Although socialization involves the learning of group culture, mores and ways of interacting, it is by no means a process in which people are deprived of agency. The account in an earlier chapter of the woman who resisted her catholic socialization illustrates this fact.

The focus of the dissertation was on the second part of the answer offered in the paragraph above; namely, the life experiences of people in support of MAiD, especially their care for dying others, spurred them to belief in the autonomy principle, and, through this medium, can be seen as one cause of the overall increase in support for MAiD. Specifically, these life experiences included a direct confrontation with mortality, which occurred when the participants cared for dying others – parents, grandparents and even strangers. The nexus of mortality and care is a vital demonstration of the ways that the characteristics of human beings – the need for personal meaning, especially during a time of death, when personal meaning is most precarious – interact with social structure (pre-existing cultural elements like the autonomy principle or structural arrangements like the gendering of care) to produce social change.

In sum, as I have attempted to show in this dissertation, critical realism offers a way to continue the spirit of social psychology. Ultimately, in my view, social psychology is a way to grasp the most pressing social problems of our times without losing sight either of the opportunities that individuals have to determine their own lives or the ways that their choices are shaped by social forces beyond their control. Why might this be important? To return briefly to the ethical reflection that started this dissertation, the advantage of such a social psychological framework is that it allows for the eventual development of ethical solutions that are sensitive to the lived experiences of individuals, while also acknowledging the structural, and in this sense, fundamentally collective dimensions of those problems and their solutions.

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## APPENDIX A: LIST OF SECONDARY DOCUMENTS

<b>Title</b>	<b>Document Type</b>	<b>Source</b>	<b>Year</b>
Allow assisted dying for all who choose it - A Brief to the Special Joint Committee on Physician-Assisted Dying	Brief	BC Humanists' Association	
Statement of Principles on Euthanasia and Assisted Suicide	Policy Statement	Canadian Association of Social Workers	
Statement from Cardinal Thomas Collins, Archbishop of Toronto on passing of Bill C-14 – legalization of euthanasia/assisted suicide	Policy Statement	Catholic Archdiocese of Toronto	
CMA Code of Ethics (2004)	Policy Statement	Canadian Medical Association	
Principles-based Recommendations for a Canadian Approach to Assisted Dying	Brief	Canadian Medical Association	
Canadian Mental Health Association's Position Paper on Medical Assistance in Dying (MAiD)	Policy Statement	Canadian Mental Health Association	
MAiD and Mental Illness: Critical Thoughts, Constructive Thoughts	Ethics Paper	Journal of Ethics in Mental Health	
Input on Proposed Regulations for the Monitoring of Medical Assistance in Dying	Brief	Canadian Society of Palliative Care Physicians	
CSPCP Member Survey - Medical Assistance in Dying (MAiD)	Report	Canadian Society of Palliative Care Physicians	
CSPCP Position Statement – The Practice of Euthanasia and Assisted Suicide	Policy Statement	Canadian Society of Palliative Care Physicians	
Address of John Paul II to the Members of the Pontifical Academy for Life	Address	The Holy See	
PDAM Evidence February 1, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence February 2, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence February 3, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence February 4, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	

PDAM Evidence January 18, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence January 25, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence January 26, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence January 27, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
PDAM Evidence January 28, 2016	Evidence Presented to Committee	Special Joint Committee on Physician-Assisted Dying (PDAM)	
In Need of Assistance on Euthanasia	Editorial	Globe and Mail	1994
Let Parliament Decide	Editorial	Globe and Mail	1994
Euthanasia, Limited	Editorial	Globe and Mail	1995
Time to Empower Angels of Mercy	Editorial	Globe and Mail	1996
Austin Bastable's Dying Will	Editorial	Globe and Mail	1996
Dignity in Death May Depend on Friends	Editorial	Globe and Mail	1999
Consider Euthanasia	Editorial	Globe and Mail	2001
Autonomy in Death, with Safeguards	Editorial	Globe and Mail	2011
Not A Verdict on Euthanasia	Editorial	Globe and Mail	1950
Beyond Judicial Domain	Editorial	Globe and Mail	1992
Sue Rodriguez's Last Request	Editorial	Globe and Mail	1993
Courts, Legislatures, and Assisted Suicide	Editorial	Globe and Mail	1997
Euthanasia, Mercy and Robert Latimer	Editorial	Globe and Mail	1997
Latimer's Sentence on Trial	Editorial	Globe and Mail	1997
The Pain of Dying	Editorial	Globe and Mail	2002
Mr. Fariala's Suicide	Editorial	Globe and Mail	2004
Let Canadians Die with Dignity	Editorial	Globe and Mail	2011
Freedom from Inescapable Pain	Editorial	Globe and Mail	2012
Australian, 104, Dies in Assisted Suicide in Switzerland	News article	CTV News	2018
N.S. Man Ready for Assisted Death - But there's no one to help him Die	News article	CBC News	2018
Saskatoon Man Arrested After Witnessing Wife's Suicide	News article	Globe and Mail	2018
Searching for an Alzheimer's Cure while my Father Slips Away	News article	The Guardian	2018
The Doctor who Took on Death	News article	Maclean's	2018
The Damage Done	Book	Go Gentle Australia	2016

Andy Squires	Online Testimonial	Friends at the End (FATE) - UK	
Anonymous	Online Testimonial	Friends at the End (FATE) - UK	
Heather Pratten	Online Testimonial	Friends at the End (FATE) - UK	
Jason Barber	Online Testimonial	End of Life Choice - New Zealand	
John Close	Online Testimonial	Dignity in Dying - UK	
My Aunt's Struggle with Assisted Suicide	Online Testimonial	LA Times	
Margaret John	Online Testimonial	Dignity in Dying - UK	
Pam Parlanti	Online Testimonial	Dignity in Dying - UK	
A Man of High Principles	Online Testimonial	Dying with Dignity - Canada	
Protect Yourself: Your Rights as a Patient	Online Pamphlet	Dying with Dignity - Canada	
Assisted Dying Guidelines in Place for All Canadian Provinces	News article	CBC News	
Bill-84 An Act to Amend Various Acts with Respect to Medical Assistance in Dying	Bill	Legislative Assembly of Ontario	
Right to Die Society Canada Newsletter October 2	Newsletter	Right to Die Society Canada	
Brief to the Special Senate Committee on Euthanasia and Assisted Suicide	Brief	Canadian Unitarian Council	
Factum of the Intervener - Canadian Unitarian Council	Supreme Court Factum	Supreme Court of Canada	
Assisted Suicide & Euthanasia - A Proposal for Restructuring the Criminal Code of Canada	Online Article	Humanist Perspectives	
Bill C-14 An Act to Amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying)	Bill	Forty-Second Parliament of Canada	2016
Changing the Paradigm of Advanced Directives to Avoid Prolonged Dimension	Blog Post	Norman Cantor	2017
Completing Life with Dignity in Canada - Doug Thomas	Online Article	Huffington Post	2013

## APPENDIX B: EVOLUTION OF THE RESEARCH DESIGN AND TABLE OF RESEARCH QUESTIONS

Drawing from critical realism, symbolic interactionism, psychoanalysis and the sociology of morality, the initial research question was framed in terms of emotion. One shortcoming in the sociology of morality is that there are few models that explored how emotion and reflexivity interacted to produce moralities. In response to this gap, I started with the following three research questions:

- 1) Which emotions motivate pro-Euthanasia adherents to commit themselves to that ethical position?
- 2) How have these emotions emerged from the life-circumstances of the individuals in the study, as these individuals have engaged consciously and unconsciously with structure, culture and identity in their lives?
- 3) At an aggregate level, is there an identifiable cluster of emotions shared by people committed to pro-Euthanasia?

In terms of methodology, these questions were developed initially within an extended-case method, rather than Grounded Theory. The extended case method (ECM) design involves using an initial or “favourite” theory to analyze a case, and then using the results of that analysis to modify the existing theory (Burawoy 1998). Pilot interviews and informal conversations as the work progressed revealed that ECM was inappropriate to the project. ECM follows a logic of “casing” that was ultimately at odds with how I was proceeding in the research. Furthermore, my initial conceptualization of the field, which I originally thought was a theory, provided a theoretical frame – a useful starting point, but not explanatory enough to construct an ECM study.



Describing how cases are constructed in ECM, Tavory and Timmens note that “Being immersed in one’s favourite theory with a sense of clear theoretical case boundaries, the ethnographer swoops down on an empirical site that seems to behave in a theoretically anomalous manner. (...) Casing in ECM consists of elaborating general theoretical constructs with specific empirical instances.” (Tavory and Timmermans 2009:3). For ECM to work, both theory and empirical instances need to be well-defined from the outset. There needs to be a theoretical narrative, which both sets boundaries on the empirical world and explains what is occurring within those boundaries, and empirical observations that test those boundaries: “ECM thus treats ethnographic field as a way to re-think the boundaries of the case already implicit in the narrativity of theory.” (Tavory and Timmermans 2009:3).

The research questions originally proposed were far too open to be answered effectively using ECM.<sup>50</sup> The literature did not provide existing theories or case studies in this vein. The original formulation of the project consequently contained an un-resolved tension between developing a formal theory of emotions, morality and social change, and the need to delimit the case of the Canadian right-to-die movement.

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<sup>50</sup> To use ECM, I would have had to have in hand a complete theory of the specific emotions motivating pro-euthanasia sentiment, as well as a theory of how those emotions emerged specifically from their historical and social context. In his most iconic use of ECM, *Manufacturing Consent* Burawoy, Michael. 1979. *Manufacturing Consent: Changes in the Labor Process under Monopoly Capitalism*. Chicago: University of Chicago Press. Burawoy uses a “neo-Marxist theory of work relations” to re-conceptualize work in a Chicago engine factory; providing a counter-narrative to the existing Symbolic Interactionist theory of labour relations in the factory, and “tying the field to existing theory” Tavory, Iddo and Stefan Timmermans. 2009. *Two Cases of Ethnography: Grounded Theory and the Extended Case Method*. Thousand Oaks: SAGE Publications.. For Burawoy’s approach to work, he needed a well-developed theory of labour-relations, as well as a well-defined, empirical case.

The research design of the project consequently shifted to one focused on moving from “general empirical to specific theoretical cases” (Tavory and Timmermans 2009:4). Tavory and Timmens argue that ECM and Grounded Theory Method (GTM) rely on two opposing conceptions of theoretical narrative. In ECM, theoretical narratives are arbitrary; they are not connected intrinsically to empirical cases, so research is focused on testing the fit of *a priori* theories to theoretically appropriate cases. In GTM, conversely, theoretical narratives are seen as constructed in relation to the case at hand (Tavory and Timmermans 2009:4) – hence the requirement that theories be comprehensible to those in the field (Glaser and Strauss 1967). Tavory and Timmens write: “Whereas GT practitioners do not see the narratives in the field to be deterministically ‘natural,’ they argue that social worlds continuously produce bounded narratives to further shape and enable action.” (Tavory and Timmermans 2009). What became clear to me was that in my initial construction of the research question, I took for granted that euthanasia is a moral issue. In reality, this is a narrative bounding to the empirical produced by the social relations around health care, around family and other relations, around the culture of autonomy, and around death and dying in this context. Through my own experiences with death and dying, I became implicated in the narrative construction of the empirical field.

The construction of the case then, was already more in line with GTM than it was ECM, as it proceeded from the narrative of death that was in vogue in social field of death and dying. The research questions were, in effect, asking how, given the existence of structural and cultural positions, reflexive social actors constructed the “right to die” morality. The preliminary question then, shifted from the *a priori* focus on emotions to the following:

How has the experience of caregiving, bereavement and/or serious illness shaped the issue of euthanasia for volunteers and other actors involved with pro-euthanasia organizations?<sup>51</sup>

Research Questions	Method
<p>Which emotions motivate pro-Euthanasia adherents to commit themselves to that ethical position?</p> <p>How have these emotions emerged from the life-circumstances of the individuals in the study, as these individuals have engaged consciously and unconsciously with structure, culture and identity in their lives?</p> <p>At an aggregate level, is there an identifiable cluster of emotions shared by people committed to pro-Euthanasia?</p>	Extended case method – Original Research Question
How has the experience of caregiving, bereavement and/or serious illness shaped the issue of euthanasia for volunteers and other actors involved with pro-euthanasia organizations?	Grounded Theory – Initial Research Question
Why does autonomy emerge as a significant aspect of the experience of death and become part of the pro-MAiD identity	Grounded Theory – Emergent Question
How does the humanist moral background shape the conception of autonomy in the pro-MAiD identity?	Grounded Theory – Emergent Question

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<sup>51</sup> This question signalled a change in casing from the justification of euthanasia as an illustrative case of a theory of morality, to an exploration of why and how, in the context of social life in the twentieth and twenty-first century, euthanasia was constructed as a moral good. In this regard, the case is a result of me “starting from where I am,” or taking my personal biography as the initial context of qualitative research (Lofland and Lofland, 11-15). While I myself have never been involved in pro-euthanasia organizations or movements, I became aware of the issue when I witnessed the prolonged death of a family member.