Physician-Assisted Dying and The Politics of End-of-Life Care

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DEDICATION

For my mother, Linda Lisman,

who died in 2011 and opened my eyes to the pains of dying.

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ABSTRACT

In June 2016, the Parliament of Canada legalized the practice of physician-assisted dying. The key event that made this possible was the Supreme Court case of *Carter v. Canada*, a landmark litigation that successfully challenged the constitutionality of the Criminal Code prohibitions on physician-assisted dying. This thesis provides an in-depth, sociological examination of the Carter case using stakeholder interviews with key participants, document analysis of all of the legal artefacts generated by the case, and observation of the Supreme Court of Canada hearing of the case. I examine the dynamics of *Carter* in order to theorize about the central phenomena that constitute the contemporary debate over physician-assisted dying in the 21st century. After an introductory chapter in which I situate this thesis within the larger scholarly conversations on physician-assisted dying specifically and end-of-life care more generally, the findings are presented in three article-length manuscripts. While physician-assisted dying is an ancient topic, the medico-legal regimes of the practice are a relatively recent phenomenon. There is thus new knowledge and data on the practices that have never existed before. In the first article, I investigate stakeholders' use of this new knowledge from permissive jurisdictions around the world. I found that opponents and proponents constructed divergent cultural meanings about physician-assisted dying using the new knowledge. In the second article, I ask how proponents of physician-assisted dying articulated 'suffering' with the role and place of medicine at the end of life. In so doing, I highlight proponents' discursive mobilization of the construct of suffering, a central discursive trope of the right-to-die movement. I found that proponents made productive use of the framework of the medicalization of dying to advance their cause. In the third article, I analyze the ways in which opponents constructed the boundaries between physician-assisted dying and other end-of-life care practices whose outcome was likely to be death. In the same article, I also analyze proponents' discourse on this matter. While this issue has been much discussed in the bioethics and legal literature, little attention has been paid to how it unfolds in the context of an instance of a social movement to decriminalize or legalize physician-assisted dying. I found that while opponents defended the ethical distinction between physician-assisted dying and the other end-of-life care practices, proponents rejected it, considering them all variants of the same practice. In the concluding chapter, I discuss the sociological implications of my findings, the limitations of this research and potential directions for future research on physician-assisted dying. *Carter v. Canada* has radically altered the landscape of end-of-life care for Canadians in the 21st century. In documenting and analyzing the dynamics of the case, this thesis contributes to a deeper understanding of this key event in the history of death and dying in Canada.

RÉSUMÉ

En juin 2016, le Parlement du Canada légalisait l'aide médicale à mourir. Cet évènement charnière fut rendu possible par l'affaire *Carter c. Canada* à la Cour suprême du Canada, un litige historique qui remit en question avec succès la constitutionnalité de l'interdiction de l'aide médicale à mourir par le Code criminel. Cette thèse présente un examen sociologique en profondeur de l'affaire *Carter* en se basant sur des entretiens avec des individus y ayant joué un rôle central, sur une analyse documentaire de tous les documents légaux générés par ce cas, et sur l'observation des audiences relatives à cette affaire. Nous examinons les dynamiques de l'affaire *Carter* afin de théoriser sur le phénomène important que constitue le débat contemporain de l'aide médicale à mourir au 21^{e} siècle. Après un chapitre d'introduction qui situe cette thèse au sein de conversations académiques plus larges sur l'aide médicale à mourir et plus généralement sur les soins en fin de vie, les résultats de recherche sont présentés dans trois manuscrits au format d'article scientifique. Bien que l'aide médicale à mourir est un vieux sujet, l'existence de régimes médicaux-légal pour cette pratique est un phénomène relativement récent, ce qui mène à l'apparition de nouvelles connaissances et données sur des pratiques n'ayant jamais existé auparavant. Le premier article étudie l'utilisation par les parties prenantes de ces nouvelles connaissances dans des juridictions permissives à travers le monde et découvre que la construction de la signification culturelle de l'aide médicale à mourir basée sur ces nouvelles connaissances diverge entre ses opposants et ses partisans. Le deuxième article s'intéresse à la manière dont les partisans de l'aide médicale à mourir articulent la relation entre la « souffrance » et le rôle et la place de la médecine en fin de vie. Il met ainsi en lumière la mobilisation discursive du construit de la souffrance par les partisans de l'aide médicale à mourir, un élément discursif central du mouvement pour le droit à mourir. Nous trouvons que les partisans de l’aide médicale à mourir ont fait un usage productif du cadre de la médicalisation de la mort pour avancer leur cause. Le troisième article analyse les moyens suivant lesquels les opposants ont construit les démarcations entre l’aide médicale à mourir et d’autres types de soin en fin de vie dont le résultat le plus probable est la mort. Ce même article analyse le discours des partisans sur cette question. Bien que cette question ait déjà été discutée largement dans la littérature en bioéthique et en droit, peu d’attention a été accordée à la manière suivant laquelle elle se manifeste dans le contexte du mouvement social pour la décriminalisation ou la légalisation de l’aide médicale à mourir. Cet article découvre que bien que les opposants ont défendu qu’il existait une distinction éthique entre l’aide médicale à mourir et d’autres formes de soin en fin de vie, les partisans ont rejeté cette distinction, considérant ces pratiques comme différentes variantes d’une même pratique. Le chapitre final conclut par une discussion sur les implications sociologiques des résultats présentés dans cette thèse, les limites de cette recherche et les directions potentielles que pourrait prendre la recherche future sur l’aide médicale à mourir. *Carter c. Canada* a altéré radicalement le paysage des soins en fin de vie pour les Canadiens au 21^{e} siècle. En documentant et en analysant les dynamiques de ce cas, cette thèse contribue à une meilleure compréhension de cet évènement clé dans l’histoire de la mortalité et de la mort au Canada.

STATEMENT OF ORIGINALITY AND CONTRIBUTION OF AUTHORS

This thesis has been written and organized in the manuscript-based (article-based) format. It includes three articles that have been prepared as stand-alone papers for peer-reviewed, journal publication, plus introductory and concluding chapters. This thesis emerged out of a larger Canadian Institutes of Health Research (CIHR)-funded project that I initiated with my supervisor, Dr. Jennifer Fishman. I am the primary author of the three articles that comprise this thesis. I designed the research protocols for both the larger project and this thesis under the aegis of Dr. Fishman. I collected all of the empirical data for this thesis myself, after which I conducted the initial and primary analysis of the data. I also wrote the first full drafts of the articles.

My co-authors for the articles are Drs. Jennifer Fishman and Mary Ellen Macdonald, co-Principal Investigators of the larger project, and Dr. David Kenneth Wright, who was a postdoctoral fellow member of the research team. My co-authors provided crucial advice and feedback on the analysis and helped improve the clarity of my arguments and the structure of the articles. All authors reviewed and approved the final manuscripts. The first article has been published in *Mortality*, the second one has been accepted with minor revisions for publication in *Social Science & Medicine*, and the third will be submitted to a peer-reviewed journal shortly.

This thesis represents original research on the court case of *Carter v. Canada*, a landmark litigation that resulted in the decriminalization of physician-assisted dying in Canada in 2015. The data analyzed consist of all of the legal documents generated by the case as well as 42 in-depth interviews with its key participants. I also attended and observed the Supreme Court of Canada hearing on the case in 2014. These data have never been analyzed or published by anyone else and this thesis is, to the best of my knowledge, the first in-depth, empirical study of the landmark court case.

GLOSSARY

BCCA: British Columbia Court of Appeal

BCCLA: British Columbia Civil Liberties Association

BCSC: British Columbia Supreme Court

EOLC: End-of-Life Care

LAWER: Life-ending Act Without the Explicit Request of patient

OHA: Oregon Health Authority

ODDA: Oregon Death with Dignity Act

PAD: Physician-assisted dying[1]

PAS: Physician-assisted suicide

SCC: Supreme Court of Canada

STS: Science and Technology Studies

WDDA: Washington Death with Dignity Act

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[1] Euthanasia and assisted suicide have been variously referred to as ‘aid-in-dying,’ ‘assisted dying,’ ‘medical aid-in-dying,’ ‘medical assistance in dying,’ ‘death with dignity,’ ‘therapeutic homicide,’ ‘medical killing’ and other terms in academic as well as public and policy conversations. In this thesis, I use the term ‘physician-assisted dying’ exclusively in order to stay faithful to the term that was used by the *Carter* participants while remaining cognizant of the fact that the labeling of the practice is itself a deeply contested issue within the debate (see chapters 2 and 4).

CHAPTER 1

INTRODUCTION

On June 17, 2016, Canada became the latest jurisdiction in the world to legalize the practice of physician-assisted dying (PAD). Canada is but one in a growing number of countries in which the right-to-die movement has recently found legal and legislative success (see Table 1 below). As PAD acquires the status of a 'social problem' that is mobilized by, and at the same time, mobilizes a significant number of actors in more and more societies, understanding its contemporary articulation takes on a renewed sociological urgency. This thesis takes up this challenge by examining in depth the dynamics of the key event that made the legalization of PAD possible in Canada: *Carter v. Canada*, the landmark litigation that successfully overturned the century-old Criminal Code prohibitions on assisted dying.

Physician-assisted dying includes the practices of euthanasia and physician-assisted suicide. How it is enacted or carried out differs across policy regimes but in essence, the practice entails a patient requesting and receiving from a physician a lethal cocktail of medications with which to hasten death. Different regimes legitimize different reasons for such request. In Oregon, for example, patients must have a prognosis of dying within six months. In the Netherlands, patients must be suffering "unbearably." These regimes are relatively recent phenomena, notwithstanding the fact that PAD is a topic that has been debated since Greek and Roman antiquities. As Table 1 shows, the 9 jurisdictions that have passed legislation legalizing PAD did so within the past 22 years. There is, therefore, a new state-sanctioned form of death and dying that has emerged only in the late 20th and early 21st century. More important in the context of the debate over legalization, these regimes have provided opponents and proponents with new knowledge about PAD which has hitherto never existed.

Year of Decriminalization or Legalization*	**Jurisdiction**
1918	Switzerland[1]
1994	Oregon[2]
1996	Northern Territory of Australia[3]
1997	Colombia[4]
2002	The Netherlands
2002	Belgium
2008	Washington
2009	Luxembourg
2009	Montana[4]
2013	Vermont
2014	New Mexico[5]
2015	California
2016	Canada[6]

* Decriminalization refers to the removal of criminal sanctions. Decriminalization typically, but not always, occurs through a court decision that strikes down the impugned law. Legalization, on the other hand, refers to the creation of a regulatory regime; only legislatures have the authority to legalize a practice.

[1] In Switzerland, aiding and abetting suicide would attract criminal liability only if it is done for selfish reasons. This provision has always been part of the federal penal code.

[2] The Oregon Death with Dignity Act first passed in 1994 although its implementation was held up by a legal challenge and the state legislature until 1997.

[3] The legislature of the Northern Territory of Australia legalized assisted dying in 1996. The legislation, however, was overturned a year later by the federal government in Canberra.

[4] Assisted dying has been decriminalized only through court decisions in Montana and Colombia. The governments in these jurisdictions have not passed a legislation on assisted dying.

[5] A lower court in New Mexico decriminalized assisted dying in 2014 although this ruling was subsequently overturned by the state Supreme Court in 2016.

[6] The provincial government in Quebec passed a legislation on 'medical aid-in-dying' in 2014. However, its legal status at the time was unclear since the Criminal Code prohibitions on PAD were still in place then.

Table 1. Permissive regimes of euthanasia and physician-assisted suicide around the world.

The debate on PAD is situated within the changing historical context of death and dying. Medicine, in particular, has had a profound impact on the contemporary experience of dying in Western, developed societies. While it is not solely responsible for the historical transformation of death and dying, there is agreement among authors that it is a major, if not *the* major phenomenon, that has transformed death and dying over the course of the 20th century

(Broom, 2015; Howarth, 2007). Understanding the debate on PAD, therefore, requires questioning how stakeholders view the role and place of medicine at the end of life. One way of unpacking such a question can be accomplished by analyzing PAD proponents' discursive mobilization of the construct of 'suffering.' As Lavi (2001, 138) argues, the right-to-die movement must be properly seen "in the medical context in which it arises and primarily as a solution to the problem of pain in dying."

The debate on PAD also implicates the debate about the ethicality and legality of other end-of-life care (EOLC) practices whose outcome is likely to be death. These practices include withholding and withdrawal of life-sustaining treatment, palliative sedation, and the use of opioids in potentially fatal dosages. The relationship between PAD and these other EOLC practices becomes salient within a politico-legal context in which assisting in the suicide of another person is legally prohibited. Thus, the extent to which these other EOLC practices constitute medical measures to hasten death is an issue ripe for debate. While this issue has been much discussed in the bioethics and legal scholarship, less attention has been paid to how it unfolds in the context of a successful movement to decriminalize and legalize PAD.

The overarching aim of this thesis is to analyze the central phenomena that constitute the debate on PAD. Three interrelated but distinct research questions flow from this aim: first, I ask how stakeholders use the new knowledge from the permissive jurisdictions to promote or oppose the decriminalization of PAD; second, I ask how proponents construct the relationship between 'suffering' and the role and place of medicine at the end of life; and third, I ask how stakeholders dispute the boundaries between PAD and other EOLC practices whose outcome is likely to be death. The case of *Carter v. Canada* provided me with an empirically rich opportunity to answer these questions. I collected all of the legal documents generated by the case, conducted in-depth interviews with 42 of its key participants, and attended the Supreme Court of Canada hearing of the case. To help guide my analysis, I adopted a set of heuristics from the case study methodology in the social sciences and the studies of discourse in the sociology of knowledge. I answer the research questions in the three empirical articles that constitute the main body of this thesis. Theorizing was further facilitated by literatures in medical sociology, social studies of death and dying, law and society, science and technology studies, and bioethics.

In the rest of this introductory chapter, I provide readers with more details on the socio-historical context of PAD, focusing in particular on the medical transformation of death and dying over the course of the 20th century and the global activities of the right-to-die movement in the legal arena. I then describe the design of this research and provide an overview of the three articles.

Death and Dying in Contemporary Western Societies

It is often remarked that death is the great equalizer: It is the one event from which none of us is excused. Nonetheless, although all of us die eventually, throughout history we have not all died in the same ways (Kellehear, 2007). Multiple forces contribute to the production of different ‘deathways’ (Walter, 1994) and result in different forms of death at various historical times and places. Within the social studies of death and dying, Ariès’ (Ariès, 1981) formulation of the ideal types of the ‘tame death’ and the ‘wild death’ is perhaps the most recognized contribution to understanding the historical changes in the human experience of dying in Western societies. Death in the Middle Ages, for Ariès, was ‘tame’ insofar as the dying individual had control over the last days of her life; the dying person herself announced her impending death; and she summoned families and friends to say farewell and ask for forgiveness. She died at home, in her own community. In contrast, contemporary dying for Ariès is one that is 'wild.' It is characterized by its institutional location and technological dependence. It is death that he saw as ignoble, inhumane, and solitary.

The change from 'tame death' to 'wild death' was made possible through the inter-related processes of the secularization of society and medicalization of life, along with the dramatic increases in life expectancy over the course of the 20th century. The secularization of society refers to the decreasing significance of religion in people's lives and is closely tied to the medicalization of life, "the process by which medical definitions and practices are applied to behaviors, psychological phenomena, and somatic experiences not previously within the conceptual or therapeutic scope of medicine" (Davis, 2010, 211). Thus, where religion (or, more specifically, the Judeo-Christian religious traditions) used to provide meaning to the experience of dying, it is medicine now that functions as the social institution of control *par excellence* and provides the symbolic framework of reference for dying individuals in Western societies. Indeed, medicine has replaced religion as the central institution of control over most life processes (Turner, 1995) such that medicalization can now be said to be the distinguishing characteristic of contemporary life (Conrad, 2013). Further, the medicalization of death and dying is closely intertwined with its institutional location. The hospital is now the most common place of death in many developed countries, including Canada (Gruneir et al., 2007; McNamara & Rosenwax, 2007; Tait & Hodges, 2009).

The Medical Transformation of Death and Dying

In wealthy, developed countries, the average life expectancy is now over 80 years, in comparison to 50 years for persons born in the year 1900 (Broom, 2015). Much of this increase has been attributed to improvement in public health (McKinlay & McKinlay, 1977). In the context of death and dying, increased life expectancy is significant because of the underpinning epidemiological transition in the population burden of diseases. Where most deaths used to be abrupt and the result of accidents and acute illnesses, contemporary deaths now take place at older ages, typically after a prolonged period of debility from chronic illnesses. There is, in other words, a misalignment of social and biological deaths in the contemporary dying experience (McNamara, 2001). Norwood (Norwood, 2009, 7) defines social death as "a series of losses – loss of identity and loss of the ability to participate in social activities and relationships that eventually culminates in perceived disconnection from social life." For many individuals with chronic, life-limiting illnesses, social deaths often precede their biological deaths as part of their illness trajectories.

Many sociologists view the medical management of chronic illnesses and, by extension, death and dying critically. This is especially true of many of the early medical sociology studies on hospital deaths. In their classic work, for example, Glaser and Strauss (1966, 4) wrote that while "doctors and nurses in training do have some experience with dying patients, the emphasis is on the necessary techniques of medicine or nursing, not on dying itself." In some instances, healthcare professionals treated dying patients as if they were already dead (Sudnow, 1967). Sudnow described observing a nurse who attempted to close the eyes of a dying patient because rigor mortis would make it more difficult to do so after death. Such practices were part and parcel of the paternalism that prevailed in medicine for much of the

20th century. The rise of patients' rights movements has, however, forced medicine to reckon with the notion of patient autonomy (i.e., patient's control over the decision-making process) and transformed the patient-provider relationship in the second half of the 20th century (Zussman, 1992). Indeed, the notion of autonomy animates the hospice and palliative care movement, which many commentators see as one societal response to the perceived historical mismanagement of dying by many healthcare providers.

The hospice and palliative care movement has its origins in the founding of the first modern hospice, St. Christopher's Hospice, in London in 1967 by Dame Cicely Saunders. Saunders sought to create a safe space for dying patients in which comfort and quality of life would be prioritized over the goal of curing or extending life. Saunders' approach to care – now popularly known as 'palliative care' – subsequently found passionate adherents throughout the world, including Canada. The global success of palliative care has set the medical standard for what it means to have a 'good death' (Livne, 2014) and at the same time contributed to the promulgation of what Walter (1994) calls the 'revivalist discourse,' a way of thinking, feeling, and acting that encourages individuals to see the process of dying as an opportunity for personal growth and re-affirmation of social bonds. It is an ideology in which knowledge and control are foregrounded as means for attaining the good death (Field, 1996).

The success of the hospice and palliative care movement has not come without criticisms, however. For one, palliative care's ideology of the good death is more easily realizable in theory than in practice (Clark & Seymour, 1999). For example, in palliative care the good death is predicated upon an open awareness and acknowledgement of one's impending death. Some dying patients, however, see such practices as alien and contradictory to their own values (Gott et al., 2008). Additionally, some palliative care interventions have been subject to much ethical and legal debate. These include the practice of putting patients under deep sedation until death (known as palliative or terminal sedation) and the practice of administering opioids in potentially lethal dosages. These interventions are typically given to patients whose suffering is intractable. Nonetheless, because they could hasten the death of the patient, they end up being what Magnusson (2006) calls the ‘devil’s choices’ in medicine. They are choices “coerced by circumstances beyond one’s control, and all the more terrible by the conviction that tragedy will follow, whichever option is taken” (Magnusson, 2006, 559).

The emergence of new technologies to extend or support life constitutes another significant dimension of the medicalization of dying. Indeed, such medical technologies as mechanical ventilators have spawned new practices, forms of dying, and ethical dilemmas (Seymour, 2007). The withdrawal of life support now frequently precedes deaths in the Intensive Care Units of hospitals (Slomka, 1992). Being suspended in a neurovegetative state is perhaps the most dramatic example of how a new form of existing has been brought into being through the use of these technologies. It is not hard to see, then, how the use of these technologies has provoked ethical unease among both physicians and patients alike and formed the impetus for many legal battles between patients (or their substitute decision makers) and healthcare providers (Jasanoff, 2009). Moreover, these medical technologies have served only to increase the gap between social and biological deaths.

The right-to-die movement positions itself as another societal response to the ‘wild death’ of our era. Indeed, for some writers, PAD and palliative care are actually two strategies in pursuit of the same aim: the realignment of social and biological deaths (Norwood, 2009;

Seale, 1998). In the case of palliative care, all of the actors involved attempt to push back social death as close as possible to the point of biological death. PAD on the other hand, can be seen as an explicit attempt to bring forward one's biological death to coincide with the onset of social death. As Seale (1998, 7-8) notes, both palliative care and PAD in fact share "a common root in the desire to sustain the social bond and preserve an intact narrative of self-identity up to the point of death." Despite this common root, however, the hospice and palliative care movement has always been opposed to the legalization of PAD. Cicely Saunders was a lifelong opponent of PAD (Clark, 2007) and one of the most oft-used definitions of palliative care explicitly states that its professionals do not seek to hasten death (World Health Organization (WHO), 2016).

The Move towards Legalization of Physician-Assisted Dying

The idea of assisted death can be traced back to the time of Roman and Greek antiquities (Van Hooff, 2004). Indeed, the term 'euthanasia,' from the Greek word meaning 'good death,' first appeared in the fourth and third century BCE. Euthanasia, however, had a very different meaning then. According to Van Hooff, euthanasia was understood simply to be death without suffering or death in luxury (as opposed to a death hastened by a physician). There is considerable evidence that during these times, many Greek and Roman philosophers did not oppose euthanasia (Rosenfeld, 2004). It was not until the time of Hippocrates, with his famous injunction of 'do no harm' to patients, that physicians began to reconsider their support for assisted dying (Rosenfeld, 2004). From then on, the practice of PAD has largely been rejected by philosophers and physicians, despite pockets of acceptance.

It is impossible to speak of the history of assisted death without implicating another concept: suicide. Hacking (2008, 9) notes that our contemporary conception of suicide is pervaded by the “trio of depression, despair, and a cry for help.” However, much like the term ‘euthanasia,’ the cultural meaning of suicide was very different in the antiquities. Suicide was not seen as a categorical evil; the moral imperative of the time was less on living *per se*, than on *living well* (Lewy, 2011). From the fourth century on, however, the Christian Church strongly condemned suicide, considering it a usurpation of God’s prerogative to give and take away human life. The criminalization of suicide began in the 19th century where everything that was considered socially deviant began to be counted by the State (Hacking, 2008). It was during this time that many governments started proscribing the act of suicide itself, along with the attendant acts of attempting suicide and assisting suicide, declaring them illegal and bringing them under the prohibitive framework of criminal law.

Today, suicide is no longer illegal in many jurisdictions. The medicalization of deviance, the construction of such ‘deviant’ acts as suicide or attempted suicide as a medical problem (Conrad & Schneider, 2010), went hand in hand with the decriminalization of the act. Encouraging persons to live and shifting control over the act of suicide to the fields of mental health and psychiatry are two of the most important policy implications of the medicalization and decriminalization of suicide. In Canada, the decriminalization of suicide and attempted suicide took place in 1972. Assisting in the suicide of another person, however, remains trapped in the punitive matrix of criminal law for most societies, including Canada until this year.

The Emergence of Medico-legal Regimes of Physician-Assisted Dying

Concerted political efforts to legalize PAD began in the late 19th century and early 20th century in the United States and the United Kingdom (Emanuel, 1994). To be sure, there were earlier proposals for PAD but these were more akin to philosophical treatises than public policy propositions (Lavi, 2007). In 1906, the first ever bill to call for the legalization of PAD was defeated in the Ohio legislature (Manning, 1998). Globally, the right-to-die movement then entered a relatively fallow period of activity for much of the middle of the 20th century. Its resurgence in the second half of the 20th century has been attributed by many commentators to the escalation of the medicalization process in society, including the medicalization of death and dying (Emanuel, 1994; McInerney, 2000; Rosenfeld, 2004; Walter, 1994). Further, according to McInerney (2000), the rise of a ‘new’ type of social movement in the 1960s provided a discursive template for the proponents of PAD. These new social movements were more diffuse in organization, drawing its members from a broad spectrum of society, and placed greater emphasis on “identity, individuality, and control of one’s body” (McInerney, 2000, 138). Indeed, the right-to-die movement is, for McInerney, the “quintessential new social movement, having taken the preoccupation with resisting state control of cultural matters and reclaiming matters of identity, privacy and individual corporeality to their ultimate level” (151).

Although it was in Oregon in 1994 that the right-to-die movement first found legislative success, it is the Netherlands that has had the longest experience with the practice of PAD. The Dutch courts first laid the groundwork for legalization through a series of separate decisions from 1973 to 1985 that effectively provided physicians with a legal justification for practicing euthanasia (Lewy, 2011). In other words, a state of *de facto* decriminalization of PAD existed in the country. Decriminalization means the removal of legal sanction, while legalization refers to the creation of a regulatory regime. In 1990, the Ministry of Justice and the Royal Dutch Medical Association agreed on a new reporting policy whereby physicians were to report all instances of PAD to the local medical examiner, who would then refer the cases to the local district attorney (Griffiths et al., 2008). Physicians would not be prosecuted as long as they complied with the requirements. This policy effectively created, for the first time ever, a body of administrative data on the actual practice of PAD. In 1993, the Dutch Parliament took steps to make the reporting mandatory. Finally, in 2002, the legal criteria for requesting euthanasia were codified in the Dutch Criminal Code, criteria that have been previously worked out in the judiciary.

In the state of Oregon, voters in 1994 passed a citizen's initiative on physician-assisted suicide (PAS) by a majority vote of 51%. The implementation of Oregon's Death with Dignity Act was, however, held up in the courts and by the state legislature. In 1997, the Oregon legislature introduced a ballot measure designed to repeal the Act but it was ultimately rejected by 60% of the voters. The Act was finally implemented in late 1997 and the first 'death with dignity' in the state took place in 1998 (Oregon Health Authority, 2013). In 2002, Belgium passed a euthanasia legislation that was modeled after that of the Netherlands. At the same time, Belgium also passed another legislation enshrining the right of all Belgians to palliative care. In 2008, voters in the state of Washington passed a citizen's initiative to legalize PAS, similar to the one in Oregon. Other American states that have recently legalized PAS include Vermont, in 2013, and California, in 2015.

One of the most important policy distinctions between the regimes concerns whether or not physicians are allowed to directly administer the lethal medication to the patients. In the

American permissive regimes, physicians are only allowed to prescribe the lethal medication, which the patients must then orally administer themselves. Bioethicists have used the term ‘physician-assisted suicide’ to distinguish this practice from ‘euthanasia,’ where physicians intravenously administer the lethal medication to the patients (Van der Maas et al., 1991). The latter is the most common type of PAD practiced in the Benelux countries, although PAS is also legally permitted. All of the permissive regimes make the reporting of PAD mandatory. The emergence of these permissive regimes is critical to the debate over legalization of PAD. Not only do they function as models or exemplars for the stakeholders, either to be emulated or avoided, but their very existence has produced a plethora of scientific, biomedical, and lay knowledge of PAD that has hitherto never existed.

It’s important to briefly note here how, in many Western countries, the legal prohibition on PAD has impacted the other EOLC practices that I described earlier (i.e., withholding and withdrawal of life-sustaining treatment, palliative sedation, and the use of opioids). Many physicians, for example, are afraid of prescribing strong pain medications – because of the potential side effect of respiration suppression – for fear of running afoul of the law (Quill & Meier, 2006). Their fear may not be entirely unfounded. Alpers (1998) notes that between 1990 and 1998, there were 23 cases in the U.S. where healthcare providers have been criminally investigated for opioids use in connection with the death of their patients. Similarly, many physicians express fear about being prosecuted in cases involving the withdrawal of life support (Sulmasy, 1998). In fact, many so-called ‘right-to-die’ legal cases that have captured the attention of scholars, the media, and the public concern the withdrawal of life support (see for e.g., *Cruzan v. Director, Missouri Department of Health* 497 U.S. 261 [1990]). The legal scholars

Lemmens and Dickens (2001) have argued that no analysis of PAD can ever be complete without considering its relationship to these other end-of-life care practices.

The Canadian Context

Political efforts to legalize PAD constitute a country's 'morality policies' (Glick & Hutchinson, 2001). Morality policies are deeply contested and polarizing and, as a consequence, their passage in the legislatures is often stymied. This is certainly the case in Canada where 6 private members' bills to legalize PAD had failed in the Parliament prior to *Carter*. It is not surprising then to see the proponents of PAD turned to the court to advance their cause.

The first legal challenge to Canada's Criminal Code prohibitions on PAD was initiated by Sue Rodriguez, a British Columbia woman with Amyotrophic Lateral Sclerosis who took her case to the Supreme Court of Canada (SCC) in 1993. Rodriguez argued that Section 241(b) of the Criminal Code, which prohibited a person from aiding and abetting another person to commit suicide, impinged on her rights guaranteed under sections 7, 12, and 15 of the *Canadian Charter of Rights and Freedom.* The Charter forms part of the Canadian constitution and the sections implicated in *Rodriguez v. British Columbia* concern the right to life, liberty and security of the person, along with the right to not be subjected to cruel and unusual punishment and equality rights (please see Appendix A for a complete transcription of these Charter sections). The lower courts had ruled against Rodriguez and the SCC upheld that decision with a split of 5 to 4. The majority decision stated that although Rodriguez's rights had indeed been violated, the government had successfully demonstrated that nothing short of a blanket prohibition could protect the vulnerable from being induced to commit suicide. In 1994, Rodriguez committed suicide with the help of an anonymous physician.

The split decision in *Rodriguez v. British Columbia* and the fact that the Attorney General of British Columbia never opened a criminal inquiry into Rodriguez's death suggested a "multi-faceted uneasiness" (Campbell, 2007) with the Criminal Code prohibitions on PAD that was already prevalent in the country then. Indeed, after Rodriguez, the Senate of Canada in 1994 appointed a special committee to examine the issue of PAD, the members of which could not come to a unanimous decision with regards to the decriminalization of the practice. A majority of the members suggested no changes be made to the Criminal Code while a minority suggested otherwise (The Special Senate Committee on Euthanasia and Assisted Suicide, 1994).

The late 2000s saw a resurgence of activities among the proponents of PAD in Canada. In 2009, the *Collège des Médicins du Québec* (CMQ), the professional association representing Quebec's medical specialists, released a white paper recommending for the legalization of euthanasia (Collège des Médicins du Québec, 2009). This white paper was the impetus for the creation of a provincial special committee on PAD in the same year. The mandate of the committee was to canvas expert and public opinions on the issue. In 2012, the committee released its report, recommending for the introduction in the province of what it calls 'medical aid in dying' (Assemblé Nationale du Québec, 2012). Acting upon the recommendation of the committee, the National Assembly of Quebec subsequently passed a legislation in 2014 allowing for the practice. There was, however, much uncertainty surrounding the legislation since the Criminal Code prohibitions on PAD were still in place at the time. Nonetheless, the

Quebec government argued that since health was a constitutionally protected area of provincial competence, it had authority to legislate the matter.

Running parallel to the events in Quebec was *Carter v. Canada*, the landmark litigation that would dramatically alter the landscape of EOLC across the country and that is the focus of this thesis. *Carter* had its origins in the death of Kay Carter, a British Columbia woman with spinal stenosis who had travelled to Switzerland to die at an assisted suicide clinic in 2010. She had travelled there with family members, including her daughter Lee Carter and Lee's partner, Hollis Johnson. Soon after Carter's death, her family made her story known to the public and it became the subject of much media attention. In 2011, Lee Carter and Hollis Johnson, along with the British Columbia Civil Liberties Association (BCCLA) and Dr. William Shoichet, filed a notice of civil claim at the British Columbia Supreme Court (BCSC), the province's court of first instance, challenging the constitutionality of the Criminal Code prohibitions on PAD. BCCLA is a civil rights organization known for championing so-called 'progressive' causes and Dr. Shoichet was a family physician. A couple of months after the initial filing of the claim, Gloria Taylor who, like Rodriguez 20 years prior, had ALS, joined the claimants. Thereafter, Taylor became the public face for the case, at least until her death in 2012. The importance of Taylor's entry into the case cannot be overstated; not only did it provide the claimants with a representative of a group of persons who could putatively benefit from the establishment of a permissive regime, it also added a sense of urgency to the case because of the rapid progression of her illness. Indeed, the claimants used Taylor's illness as justification for their successful request to fast-track the case. The defendants of the case were the Attorney Generals of Canada and British

Columbia although it was Canada that led much of the defence and mobilized most of the witnesses in support of the status quo.

The *Carter* claimants challenged sections 241(b), 14 and other related provisions of the Criminal Code that collectively had the effect of making PAD illegal (please see Appendix B for a listing and description of these provisions). In *Carter*, PAD was defined to include both euthanasia and PAS, as these terms are conventionally defined and understood by bioethicists. The main thrust of the plaintiffs' argument in Carter is that the impugned provisions of the Criminal Code infringe on their sections 7 and 15 *Charter* rights (please refer to Appendix A). In 2012, Smith J., the trial judge, found for the claimants, declaring the impugned provisions to be of no force and effect in certain circumstances. She suspended the declaration of invalidity for one year to allow Parliament to respond by crafting a new legislation. She also granted Taylor a constitutional exemption to seek PAD in the meantime. At the time, the decision effectively made Taylor the only person able to seek and obtain PAD legally in Canada. Taylor, however, died in October 2012 from an infection of a perforated colon; she never had the chance or the need to exercise her constitutional exemption. The case was appealed by the federal government to the British Columbia Court of Appeal (BCCA), which, in a split 2-1 decision, overturned the trial judge's ruling. The majority decision stated that the trial judge was bound by the SCC decision in *Rodriguez*. The SCC subsequently granted the claimants leave to appeal and heard oral arguments in October 2014. In February 2015, the SCC Justices unanimously found for the claimants, overturning its own precedent in *Rodriguez* and the Criminal Code prohibitions on PAD. The SCC suspended its declaration of invalidity for year (it would later add a four-month extension) to allow the federal government time to amend the Criminal Code.

RESEARCH DESIGN

Research Questions

The overarching aim of this thesis is to analyze the central phenomena that constitute the contemporary controversy over the decriminalization and legalization of PAD. In order to accomplish this, I conducted a sociological examination into one of the most important instantiations of the controversy in recent years: the *Carter v. Canada* case. In the three articles that comprise this thesis, I address separate but related research questions. These are:

1. How did actors in the case use the new knowledge and evidence arising from the permissive jurisdictions to promote or oppose decriminalization of PAD?
2. How did the proponents of PAD articulate 'suffering' with the role and place of medicine at the end of life?
3. How did actors in the case dispute the boundaries between PAD and other EOLC practices?

Methodological Framework

For this research, I adopted a set of heuristics – sensitizing concepts that could alert me to potentially promising avenues for data collection and analysis – from the case study methodology in the social sciences as well as from the studies of discourse in the sociology of knowledge.

The case study has long been used as catch-all category for a variety of research designs and methodologies, often losing its meaning in the process (VanWynsberghe & Khan, 2007). Flyvberg (2006) observes further that the case study is often thought of as inferior to other social science methodologies. This may be true if the goal of the case study is to say something about other similar cases (i.e., statistical generalization). This is not the goal of my research.

This thesis adopts a definition of the case study proposed by VanWynsberghe and Khan: “[C]ase study is a transparadigmatic and transdisciplinary heuristic that involves the careful delineation of the phenomena for which evidence is being collected (event, concept, program, process, etc.)” (80). Within this formulation, the goal of analyzing the Carter case is not to generalize to other right-to-die movements or PAD litigations but to *theories concerning the phenomena that constitute the contemporary controversy on PAD* (i.e., generalizing to theory).

In order to be able to conduct a rigorous generalization to theory, the selection of a ‘critical case’ is important (Ruddin, 2006). A critical case is not the same as a typical or a representative case (which would be required if one were to generalize statistically). Instead, it is a case that is rich in information. In *Carter*, the scope of the actors involved and the knowledge they mobilized was extensive, especially in comparison to *Rodriguez* twenty years prior. By the time the case had reached the SCC, 97 witnesses and 26 interveners had participated in the case, apart from the claimants and the governments (for a list of the interveners, please see Appendix C). One hundred and three affidavits (i.e., written evidence) were submitted to the court. The number of expert witnesses called on by the claimants and the government alone hailed from 7 different countries. *Carter* thus afforded me with an opportunity to collect a rich body of empirical data.

To further guide my analysis, I derived insights from the studies of discourse in the sociology of knowledge. Discourse theory emerged from the attempt to understand how language and politics intertwine in the process of social transformation (Torfing, 2005). Different schools of discourse analysis emphasize different understandings of discourse, which has implications for the ways in which the analysis of data is conducted. Discourse can be understood as a noun or a verb; that is, discourse as an object or, alternatively, as a practice. Foucault-inspired discourse analysts, for example, typically treat discourse as a noun. Discourse is understood to be a set of ideological statements that formulate subject positions (Kendall & Wickham, 1998). It is a macro-level phenomenon that makes possible what is thinkable and sayable at a given historical juncture. Understanding discourse as a verb, on the other hand, means treating discourse as one practice in the broader repertoires of human actions that are used to accomplish things. Potter (1996), for example, defines discourse as *talk and text in action*. The analytical emphasis here is to understand how actors *at a specific place and time* construct different versions of reality through talk and text. This thesis hews closely to this understanding of discourse. It is important to note that both understandings of discourse are not in contradiction; they are complementary.

Discourse analysis has two main dimensions: textual and contextual (Lupton, 1992). Where the textual dimension of discourse analysis is concerned with the internal structures of discourse, the contextual dimension aims to relate discourse to the wider features of society. Formal linguistic analysis and conversation analysis are examples of schools that focus on the textual dimension. The analytical concern here is with the use of grammar, rhetorical devices, syntax and sound forms. Attending to the contextual dimension of discourse analysis, which I do in this thesis, means relating the talk and text of actors to some inferred larger phenomena in society that make that discourse meaningful. Gee (2014) provides the following set of questions to help analysts construct relevant parts of the context of what is said or written by actors: 1) Does the discursive utterance make a difference? 2) What activity is it being used to enact? 3) What identities of the actors are relevant? 4) What type of relationship does it create? 5) What normative judgment is it making? 6) How does it make or unmake connections between things? 7) How does it privilege or discount specific ways of knowing and doing? I have found these questions to be useful as a preliminary guide when coding the empirical data.

An important feature of discourse analysis as typically conducted by sociologists of knowledge is what Potter (1996) calls 'methodological relativism.' It is a methodological injunction that asks analysts to be indifferent with respect to the truth or falsity, rationality or irrationality of the actors' discourse (Bucchi, 2004). In other words, the job of the analyst is not to determine whether or not a particular claim by an actor is true or false; the analyst should attend instead to the ways in which that claim is made and to what effect. It is in this respect my thesis is different from other empirical studies of PAD. Other social scientists have analyzed the discourses in the debate over PAD in order to adjudicate which side is right or wrong or which position is (un)tenable (see, for e.g., Gandsman, 2016; Jones, 2007; Lewy, 2011). Following Gilbert and Mulkay (1984), I treat my participants' discourse as a topic, not a resource for drawing normative conclusions about the truth or falsity of my study participants' claims or the goodness or badness of particular PAD policy propositions.

Empirical Data

Data for the thesis consist all of the legal documents generated by the case and in-depth interviews with 42 key participants of the case. I also attended the SCC hearing in Ottawa on October 15, 2014 and took observation notes. Data collection spanned 21 months from July 2013 to March 2015. Prior to data collection, this study received ethics approval from the Institutional Review Board of McGill University.

The legal documents include affidavits, factums, official decisions and trial transcripts. Affidavits are statements of facts submitted as official evidence to the court of first instance. They are written by the claimants and witnesses. A claimant or witness may submit more than one affidavit and affidavits may be submitted to the appellate courts, although this is rare because the process of fact-finding is supposed to be completed at the court of first instance. Factums are position statements submitted at the appellate courts. Factums are not supposed to introduce new evidence that has not been introduced in affidavits. They may be submitted by the claimants, defendants or interveners. Interveners are persons, organizations, or governments with a vested interest in the outcome of the case. In *Carter*, a total of 103 affidavits and 36 factums were submitted to the courts. There were transcripts for 19 days of court trial, including one for the SCC hearing. All of the documents amounted to over 4,000 pages of text. Apart from the official decisions, which can be easily accessed online, I obtained all of the legal documents originating at the BCSC and BCCA levels directly from the lead Crown Counsel (i.e., prosecutor for the Attorney General of Canada). I obtained the materials generated at the SCC level directly from the Court.

For interviews, I targeted for recruitment the claimants, interveners and select lay and expert witnesses. I selected only those witnesses that had the most impact in the case. Venturini (2010, 262) argues that actors “are not born equal in controversies.” In other words, the ability to make meaningful change in a controversy is not distributed equally among the participants of that controversy. I operationalized impact according to two criteria. First, I defined as impactful those witnesses whose opinions were cited by the judges. Second, I targeted for recruitment those who had been called by the counsels for cross-examination. For those who declined to be interviewed or did not respond to my request (N=20), I made sure to recruit other witnesses who spoke on similar themes or issues in their affidavits. My recruitment process resulted in interviews with 42 participants, including 2 of the claimants, 9 of the interveners, and 31 of the lay and expert witnesses.

Although there were standard questions asked of all interview participants (e.g., how and why did you become involve in the case?), much of the interview was tailored according to each participant's legal materials. I asked participants to elaborate on their written statements (and oral statements if they had been cross-examined) and frequently played 'devil's advocate' by asking participants to address positions to which they were diametrically opposed. I conducted the interviews either in person, over the telephone or via Skype. All interviews were recorded and subsequently transcribed. Informed consent, written or verbal, was obtained from every single participant. After each interview, I wrote reflexive memos about my overall impression of the interview as well as any 'proto-analytical' ideas that might have emerged over the course of the interview.

I am cognizant of the different processes that produced the legal, documentary data and the interview data, as well as the different sociological claims that could be made with each type of data. In this study, however, the in-depth interviewing was designed from the outset to 'speak' directly to the legal data. Thus, rather than seeing the interviews as a triangulation method intended to discover the participants' 'true' perspectives, I see the interviews as providing me with another set of opportunities to observe and record participants' discursive constructions of PAD. All of the legal documents and interview transcripts were uploaded to Atlas.ti^{TM}, a qualitative data analysis software, for coding. Coding proceeded both deductively according to common themes derived from the literature (e.g., autonomy) as well as inductively for emergent themes with the help of some of the heuristics that I described in the previous section.

OVERVIEW OF THE THREE ARTICLES

In order for each article to be comprehensible on its own, some overlap and repetition of materials across the articles is inevitable. I wrote each article with specific scholarly audiences in mind. That is, each article draws from and contributes to slightly different bodies of literature. In this thesis, I use the term ‘proponents’ to describe the claimants and those other actors whose talk and text were strategically enrolled to advance the claimants’ cause. ‘Opponents,’ on the other hand, refers to the government (i.e., Canada) and the actors it enrolled to defend the status quo. My labeling of the participants as proponents or opponents is not intended to elide the diversity of opinions and positions that existed within each side in the case. I fully recognize that the witnesses and interveners might differ in the strength of their support for the claimants or the government.

In Chapter 2, I examine the nature of the expert evidence in *Carter* and how it was used by the participants in the case. My first significant finding was that the claimants used this new knowledge to pry open the legal debate on PAD that had been previously closed by *Rodriguez*. I found that the participants used the knowledge to construct different cultural meanings about PAD. The opponents constructed PAD as a practice accessed by suicidal patients, performed by physicians unskilled in palliative care, and loosely regulated by the State. The proponents, on the other hand, using the same evidence, constructed PAD as practice motivated by a patient’s rational choice, performed by caring physicians within an environment where end-of-life care had improved since legalization, and tightly regulated by the State. I argue that the (successful) ways in which proponents used the expert evidence in the case have contributed to the production and reproduction of a specific cultural script about PAD, a script that made death by way of PAD 'culturally appropriate' (Timmermans, 2005). This article contributes to studies that show how the cultural meanings of PAD are contingent on resources that are specific to a historical time and place. I presented an earlier version of this article at the annual meeting of the Canadian Sociological Association in Ottawa in May 2015. This article has been published in the journal *Mortality* in March 2016 (see Karsoho et al., 2016). Note that in this article I made the observation that PAD could potentially be legalized in Canada as a result of *Carter*. Since the publication of this article earlier this year, the federal government has passed a legislation amending the Criminal Code to allow for PAD.

In Chapter 3, I ask how proponents articulated 'suffering' with the role and place of medicine at the end of life. That is, I examine the ways in which proponents constructed the relationship between suffering and medical interventions at the end of life. This required me to grapple with such questions as: What did the proponents identify as causes of suffering at the end of life? In what ways did they suggest that medicine had been (un)successful in addressing suffering? In the context of PAD, how did the proponents conceive of the role of medicine in addressing suffering? I found that proponents saw mainstream, curative medicine as complicit in the production of suffering at the end of life. The proponents further denied palliative care's ability to relieve all suffering and even went so far as to claim that, in some instances, palliative care could produce suffering. They did not, however, reject medicine outright. Indeed, the proponents insisted on the involvement of physicians in assisted dying. They emphasized how a request for PAD could set in motion an interactive therapeutic process that could relieve suffering *even if the process did not culminate in the administration of lethal medication*. I argue that the proponents' articulation of suffering with the role of medicine at the end of life must be understood as a discourse through which one configuration of end-of-life care came to be accepted and another rejected, a discourse that did not at all challenge the larger framework of the medicalization of dying. I presented an earlier version of this article at the biennial conference of the Canadian Society for the Sociology of Health in Ottawa in May 2016 where it received the Robin Badgley Memorial Award for the best graduate student paper presented at the conference. This article has been published in *Social Science & Medicine* in December 2016 (see Karsoho et al., 2016).

In Chapter 4, I ask how the participants in the case discussed the boundaries between PAD and other EOLC practices, which included the withholding and withdrawal of life-sustaining treatment, palliative/terminal sedation, and the use of opioids. For the opponents, there was an ethical distinction between PAD and these other practices. The opponents actively policed the boundaries at three different 'sites': around the issues of physician's intent, the cause of death, and the 'naturalness' of the practices. The proponents, on the other hand, argued that there was no ethical distinction between PAD and the other EOLC practices. That is, they claimed that the other EOLC practices were, for all intents and purposes, variants of a medical assistance in dying. Proponents denied the 'naturalness' of the EOLC practices and argued that banning PAD and allowing for the other practices had created an unacceptably unjust situation for patients in Canada. They also maintained that the institutional capacity to assess the risks associated with PAD already existed in Canadian medicine because these were the risks that physicians were already accustomed to dealing with when making decisions involving the other EOLC practices. The participants' struggle over the boundaries of EOLC practices was an empirical example of what Zurabavel (1993) called 'border dispute.' Such border dispute, I argue, points to the inherent complexity in the ontological enactment of medical practices at the end of life and the discursive nature of the different EOLC categories. This article contributes to studies that show how "ethics gets done on the ground" (De Vries et al., 2006, 677) and will be of interest to empirical bioethicists and sociologists of bioethics. This article will be submitted to a peer-reviewed bioethics journal.

I conclude this thesis by summarizing the key findings of my research and elucidating their sociological implications. I then identify some limitations to the research and potential avenues for future research on PAD.

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CHAPTER 2

CONSTRUCTING PHYSICIAN-ASSISTED DYING: THE POLITICS OF EVIDENCE FROM PERMISSIVE JURISDICTIONS IN *CARTER V. CANADA*

ABSTRACT:

Since the 1990s, there has been a growing global movement to legalize the controversial practice of physician-assisted dying (PAD). In the last twenty years, 13 jurisdictions have decriminalized or legalized PAD which, in turn, have produced new knowledge on the practice. The recent case of *Carter v. Canada*, which decriminalized PAD in Canada in 2015, provides us with an empirical opportunity to investigate how actors deployed and interpreted this new knowledge. We found that actors used expert evidence from permissive jurisdictions to construct different meanings of PAD as a legalized medical practice. The opponents constructed PAD as a practice accessed by patients who were suicidal, performed by uncaring physicians unskilled in end-of-life care, and loosely regulated through a fallible regime. The proponents used the evidence to construct PAD as a practice borne out of a patient's rational choice, performed by caring physicians within an environment where end-of-life care had improved since legalization, and tightly regulated through a regime where participants function as sentries overseeing each other's actions. In the final analysis, we argue that the proponents' success in this case contributed to the production and reproduction of a specific cultural script that renders PAD culturally appropriate.

KEYWORDS: Physician-assisted dying; euthanasia; assisted suicide; Carter v. Canada; culturally appropriate death; Canada.

INTRODUCTION

Since the 1990s, there has been a growing global movement to legalize the controversial practice of physician-assisted dying (PAD), either in the form of euthanasia or physician-assisted suicide (PAS) (Flemming, 2005; Tierney, 2010). In the last twenty years, 13 jurisdictions have decriminalized or legalized PAD, most recently Canada in February 2015 and California in October 2015. Thus, while PAD is an ancient topic (Emanuel, 1994), the legal regimes of the practice are a relatively recent phenomenon. In the light of the newly 'permissive jurisdictions,' a sociological approach can bring a unique perspective to the study of PAD, one that does not aim to settle the normative questions on the practice but analyze instead the ways in which knowledge that emerged from those jurisdictions has been taken up by stakeholders in the debate over legalization elsewhere.

The recent case of *Carter v. Canada* [Carter V. Canada (Attorney General) 2015 Scc 5, 468 N.R. 2015 SCC 5 1, 2015)] provides us with an empirical opportunity to investigate how actors in one case deployed and interpreted knowledge on legalized PAD from the permissive jurisdictions. *Carter* was a recent landmark litigation that found Canada's criminalization of PAD to be unconstitutional, paving the way for a potential nationwide legalization of the practice. On 6 February 2015, the Supreme Court of Canada (SCC) ruled unanimously that the Criminal Code prohibitions on PAD infringed on Canadians' constitutional rights to life, liberty and security. PAD, as defined in the case, constitutes both euthanasia, "the intentional termination of life of a person, by another person, in order to relieve the first person's suffering" [Carter v. Canada (Attorney General) 2012 BCSC 886, 287 C.C.C. (3d) 1, (BCSC), 16] and PAS, "the act of intentionally killing oneself with the assistance of a medical practitioner or a person acting under the direction of a medical practitioner, who provides the knowledge, means or both" (ibid.,16).[1]

In this article, we show how actors in the case used expert evidence from permissive jurisdictions to construct different meanings of PAD as a legalized medical practice. We begin by describing how the proponents used the evidence to reopen the legal debate on PAD in Canada, after which we describe the types of evidence used in the case as well as the nature of its production from different permissive jurisdictions. We then show how the opponents constructed PAD as a practice accessed by patients who were suicidal, performed by uncaring physicians unskilled in end-of-life care, and loosely regulated through a fallible regime where abuse could be concealed with the complicity of state authorities. The proponents, on the other hand, used the evidence to construct PAD as a practice borne out of a patient's rational choice, performed by caring physicians within an environment where end-of-life care had improved since legalization, and tightly regulated through a regime where participants function as sentries overseeing each other's actions. In the last section, we argue that the proponents' success in this case contributed to the production and reproduction of a specific cultural script that renders PAD culturally appropriate in Canada.

REOPENING A CLOSED DEBATE AND CONSTRUCTING NEW MEANINGS OF PHYSICIAN-ASSISTED DYING

Prior to *Carter*, Canada's medico-legal landscape on PAD had been shaped by the SCC's prior ruling on the issue in *Rodriguez v. British Columbia* [Rodriguez v. British Columbia (Attorney General), 3 S.C.R. 519, (Can.)] in 1993. Sue Rodriguez, diagnosed with

Amyotrophic Lateral Sclerosis, had filed a constitutional challenge against the Criminal Code prohibitions on assisted suicide. *Rodriguez* was decided by a 5-4 vote in which the majority of the Justices found that the impugned prohibitions did indeed violate Sue Rodriguez's Charter rights to life, liberty and security of the person. However, the majority also found that the prohibitions were justified because the government had successfully demonstrated that nothing short of a blanket prohibition would protect the vulnerable from being induced to commit suicide in times of weakness. *Rodriguez* had thus closed the legal debate on PAD in Canada, at a time when a permissive regime did not yet exist anywhere in the world.[2]

The subsequent emergence of permissive jurisdictions in other countries was crucial to reopening the debate.[3] In order for the courts to take up the issue of PAD anew, the proponents of legalization had to show that there had been new 'facts' on the matter that did not exist when *Rodriguez* was decided twenty years ago. The legalization of PAD in other jurisdictions had made possible the production of new data on the practice. Legalization simultaneously creates the regulated practice, and by extension, new regulated subjects, and opens them up to social scientific inquiry. The proponents of legalization in Canada were able to frame the new empirical data resulting from legalization elsewhere as new expert evidence that they successfully used to reopen the debate.

In any litigation, expert evidence does not speak for itself. Instead, it must be communicated to the courts through witnesses. Cole (2007, 818-19) has argued that the "problem with experts for law is not so much what the evidence says, but what the expert says to the fact finder…I suggest that courts and scholars need to spend a little more time thinking about expert testimony and perhaps a little less time thinking about scientific evidence." Expert witnesses perform the crucial function of disciplining others into seeing reality in particular ways by establishing the particular "facts of the matter" that constitute that reality (Cole, 1998). A successful litigation such as *Carter* therefore has the potential to reshape our collective understanding of physician-assisted dying. Such 'constitutive' effects of a legal action have long been recognized by sociolegal scholars (e.g., Mather, 1998). A legal action can change the social order of a phenomenon while simultaneously changing the meaning of that phenomenon. In other words, a legal action can produce a new cultural script through which we can come to understand a phenomenon differently. We therefore take up the question of how actors in one PAD litigation used the new knowledge arising from permissive jurisdictions to construct various contemporary meanings of PAD.

ANALYTICAL APPROACH

Our analytical approach lies at the intersection of the sociology of scientific knowledge and 'configurational analysis of social action' (Jackson, 2014). In analysing the various claims produced by the actors in the case, we first adopt the methodological principle of symmetry first articulated by sociologists of scientific knowledge (Collins, 1983). This epistemological orientation to data analysis asks sociologists to be indifferent with respect to truth and falsity, rationality and irrationality, or success or failure (Potter, 1996). Consequently, we do not see our task in this study as adjudicating which actors or claims in the case were right or wrong. Rather, we attend closely to ways in which the 'truth' of PAD was discursively produced by the various actors.

In this study, we ran up against what Giddens has called the problem of the ‘double hermeneutics’ in social research: “[Analysts] have to interpret what is said by historical actors while keeping firmly in mind the fact that what they are interpreting are interpretations of the situations that those actors themselves have made” (1984 as cited in Jackson, 2014, 269). In other words, how does one produce a meaningful interpretation of actors’ talk in which the substance of that talk is itself an interpretation of a specific reality? One way would be to conduct a ‘configurational analysis of social action’ where actors are understood to be ‘cognitive bricoleur,’ building reality with the tools available to them (Jackson, 2014). According to this analytical approach, the work of empirical analysis “should involve delineating the resources available [to actors] and tracing the ways that they are deployed in practice” (Jackson, 2014, 269). Specifically, Jackson (2014) calls for three analytical tasks: first, the cultural resources on which actors draw must be delineated; second, the history of those resources must be disclosed; and third, the specific ways in which those resources are deployed in a concrete episode must be traced.

DATA AND METHODS

This study is part of a larger research project of public controversies on medicalized dying in Canada. Data used for this article consists of the legal artefacts generated by the litigation and in-depth semi-structured interviews with key participants. The first and second authors (HK and DKW) also attended and took observation notes at the SCC hearing on 15 October 2014. Data collection process spanned 21 months from July 2013 to March 2015. Prior to beginning data collection, this study received Institutional Review Board approval from McGill University.

The legal artefacts include trial transcripts, affidavits, factums, and official judgments, amounting to over 4,000 pages of text. We employed a purposive sampling strategy (Marvasti, 2004) to recruit participants for interviews. Our sampling strategy acknowledged that "actors are not born equal in controversies" (Venturini, 2010, 262), and our initial approach targeted only those participants who had the most impact in the case. We operationalized impact according to two criteria: those whose opinions were eventually cited by the Justices and those who were cross-examined. Our recruitment process resulted in 42 interviews with select plaintiffs, interveners, and witnesses. Informed consent, either written or verbal, was obtained from every participant.

Some participants declined to be identified by name, which presented us with a conundrum: on the one hand, all of the legal data are publicly accessible and yet some of the authors of this data whom we interviewed did not want to be publicly identified in our reports. In order to preserve their anonymity, we have decided to anonymize all data attributions, including the legal data. For each quotation presented in this article, we identify only the source of data (e.g., trial transcript, interview) and, where necessary for contextualization, their professional role (e.g., bioethicist, palliative care physician) and/or geographic location. The only exception that we make concerns institutional actors (e.g., a representative of a right-to-die organization). We feel that the identification of these organizations (not the personal identity of the representative) is important to the understanding of our analysis. All of the institutional actors we interviewed had given us permission to identify them and their organizations by name. It is worth noting that for the purpose of our analysis, our interest lies primarily not in the identity of each individual actor but rather the substantive contents of the discourses across various positions and professions.

For this article, we culled all data where discussions on expert evidence from permissive jurisdictions took place. These data were analyzed, coded and re-coded inductively to a higher-order 'interpretive codes' (Miles & Huberman, 1994) by the first author using Atlas.ti^{TM} and then presented to all of the authors for multiple rounds of further analysis. Our analysis for this article ultimately focused on what we term 'sustained moments of tension' between study participants on the issue of what PAD as a legal medical practice actually entailed. These were extended periods that occurred during the case (e.g., a cross-examination) and in our interviews where participants discursively challenged, deconstructed, and reconstructed other actors' understandings of legalized PAD.[4] The quotations that we have selected are representative of the most salient themes present in participants' sustained moments of tension.

RESULTS

We first delineate the evidence used by actors in the case and describe its historical production in the section below. In the following three sections, we discuss how our study participants engaged with the evidence to construct the meanings of PAD as a legalized medical practice that lay at three different analytical registers: at the levels of the patient, the physician, and the regime itself.

Expert Evidence from Permissive Jurisdictions in Carter v. Canada

In *Carter*, much of the expert evidence came from the first three jurisdictions to have already legalized a form of PAD: Oregon, the Netherlands, and Belgium. Less evidence came from Washington State and from Switzerland. Expert evidence on Luxembourg and Colombia was not subject to extended discussion during the case.[5] By the time *Carter* reached the SCC, the case had seen the participation of 97 witnesses and 26 interveners. One hundred eighteen affidavits were filed by the witnesses. Seventy-six were expert witnesses: 42 from Canada, 18 from the United States, 5 from the United Kingdom, 4 from Belgium, 3 from the Netherlands, and 2 each from Switzerland and Australia. Eighteen expert witnesses were cross-examined on their affidavits, including 11 who were cross-examined before the trial judge.

In the rest of this section, we describe the variety of the content of the expert evidence in *Carter*, limiting our discussion to the evidence from Oregon, the Netherlands, and Belgium on which most the discussions about PAD in permissive jurisdictions were based.

Legalization opens up a newly regulated practice and subjects it to scientific inquiry and surveillance. In the context of PAD, legalization does this in a number of ways. First, legalization vests a governmental body with the authority to oversee the practice. In all permissive regimes, physicians are required to report all cases of PAD that they carry out. In the Netherlands, physicians report to one of the five Regional Review Committees (RCCs) which evaluates all reported cases to ascertain whether or not they fall within the boundaries of the Dutch law (Griffiths et al., 2008). The RCCs are mandated to publish an annual joint report on all cases reviewed. In Belgium, the Law on Euthanasia created the Federal Control and Evaluation Commission that functions much like the RCCs in the Netherlands. In Oregon, physicians are to report to the Oregon Health Authority all prescriptions for lethal medication (Oregon Health Authority, 2006). Reports of all PAS cases are published annually by the Authority. A new type of evidence – official government data – has therefore been made possible through legalization.

Legalization also allows for arenas of research by independent or arm's length academics regarding the practice of PAD. One of the most important studies of this type is the nationwide Dutch research on the prevalence of medical end-of-life decisions. An aim of this investigation was to arrive at a reliable estimate of the incidence of PAD. How these studies estimate the rate of euthanasia and other medical end-of-life decisions is beyond the scope of this article. Suffice it to say that these studies make it possible to calculate the reporting rate of PAD cases by comparing the number of cases self-reported by physicians to the oversight bodies and the number of cases estimated in the national studies. These studies have also 'uncovered' what the researchers called 'Life-ending Acts Without Explicit Request' of patients (LAWER). LAWER refers to a situation whereby the patient's death is the result of administration of drugs and there is explicit intention on the part of the physician to hasten death but without the explicit legal request of a patient. Surveys that employ similar methodologies have also been conducted in Belgium (Griffiths et al., 2008). Together with the official government data on PAD, these data can be considered the 'primary data' upon which much of the expert evidence in *Carter* was based.

We further note that legalization not only makes a practice visible but also visible to more actors. The primary data on PAD were then subject to secondary analysis and critiques by other stakeholders. Expert evidence based on these secondary analyzes was less present but no less contested in *Carter*. Legalization also enabled the descriptions of experts' professional experience working in permissive jurisdictions, which rounded out the body of expert evidence submitted in *Carter*. Collectively, the evidence provided actors with resources to mobilize claims about the relative incidence and safety of PAD, as well as professionals' experience with its associated practices, in permissive jurisdictions.

Suicide or Rational Choice?

Our analysis shows that the actors in the case engaged the evidence to construct competing understandings of the typical patient who would access PAD (the 'PAD patient'). Canada[6] argued the PAD patient was likely to be motivated by depression or other psychiatric conditions, thereby seeing the request for PAD as suicidal ideation, deserving of mental health intervention rather than hastened death. Canada also saw the 'ambivalence' of patients who requested PAD in permissive jurisdictions as further evidence that a PAD request was a suicidal ideation. In both Oregon and Washington State, the government reports showed that not all of the patients who received prescription of lethal medication ended up using it. For one suicidologist testifying for Canada this was indication that "[a]lthough we would like to believe that the decision to hasten death by someone suffering from a terminal illness or degenerative disease is unambivalent rational decision, *different from the often changing decisions to commit suicide by people in good health*, there is no basis in fact to support this contention" (emphases added, affidavit). Thus, if a PAD request was suicidal ideation, it followed that the act of PAD itself must be an act of suicide.

The construction of PAD as suicide was expressly intended to pathologize PAD. Hacking (2008) has noted that our contemporary conceptualization of suicide is characterized by three distinct ideas: 1) suicide is caused by depression; 2) suicide thrives in a culture of despair; 3) attempted suicide can be understood as a cry for help. If a PAD request could be seen as a "cry for help," then the appropriate medical intervention would be psychiatric or psychological, rather than an "early death" (affidavit). A clinical psychologist testifying for Canada stated under cross-examination: "I think that anybody who would request physician-assisted dying under any circumstances could be referred for a mental health assessment" (trial transcript).

In stark contrast to Canada's portrayal of PAD as a suicidal act, the claimants[7] presented a view of PAD as a thoughtful and deliberate choice that reflected a set of life-long values emphasizing autonomy and self-determination. On this view, patients seeking PAD have "strong and vivid personalities characterized by determination and inflexibility. These individuals have an unusually fervent desire to control the timing and manner of death to avoid dependence on others. These preferences [reflect] pervasive and long-standing coping and personality traits" (affidavit). One retired Oregon physician also emphasized Oregon's exclusion of people with mental health issues from the PAD regime.

The construction of the PAD patient as rational and not suffering from depression led many of the claimants' expert witnesses to insist that PAD was, in fact, not suicide. As one witness deposed: "I submit that there is a difference between well-reasoned deliberation about controlling one's final days in the face of inevitable and imminent death (aid-in-dying) and suicides performed in the context of severe depression, despair and hopelessness and that evidence and argument submitted by [Canada's expert witnesses] conflate the two concepts" (affidavit). The claimants even questioned Canada's construction of the PAD patient as desiring death. Gloria Taylor was one of the plaintiffs; she had been diagnosed with ALS and stated, “I am dying. *I do not want to*, but I am going to die; that is a fact” (emphases added, affidavit).

The debate over PAD as a suicide or rational act was reflected in the struggle among our study participants over the label ‘physician-assisted suicide’ (PAS). At the beginning of an interview with an Oregon physician who had testified for the claimants, the participant asked whether she could get us “to use physician-assisted death or physician-assisted dying” instead of PAS, explaining that she had found the term PAS to be “very offensive” (interviewee 28). The first annual report prepared by the Oregon Health Authority (OHA) had used the term PAS. By 2007, however, the OHA began to use the term “DWDA [Death with Dignity Act] death” instead to describe deaths under the Act. Compassion & Choices Oregon had acknowledged to us that they were responsible for asking the state to change the name (interviewee 8). For one of Canada’s expert witnesses, Compassion and Choices’ act and the official change in name amounted to “verbal engineering” designed to “desensitize the public to what is actually going on, which is physician-assisted suicide. Because medical killing is always unpleasant, and suicide is always a tragedy” (interviewee 21). For Canada and its supporters, PAD was suicide, an act taken by a vulnerable patient; the use of terms other than physician-assisted suicide (e.g., PAD, death with dignity, aid in dying) could only be seen as an effort to mask what was “actually going on” (interviewee 21). For the claimants, however, PAD was a rational act, taken voluntarily by determined patients whose request fit with their larger life-long set of goals.[8]

Professional (In)Expertise in End-of-Life Care

One fundamental disagreement between the claimants and Canada concerned what it meant for a physician to have moral and clinical expertise in end-of-life care. This disagreement played out most vividly in discussions on two subjects: first, patient's decision-making competency and second, palliative care.

There are multiple factors that could affect a patient's competency in decision-making. One that was raised frequently by Canada was the potential impact of depression and other psychiatric conditions on patient's competency. An Oregon physician who was an expert witness for Canada relayed the following story in his affidavit: a 76-year-old patient, for whom he was the family physician for over ten years, was diagnosed with malignant melanoma. He referred the patient to both radiation and medical oncology. After treating the patient, the radiation oncologist noted in her record that the patient was depressed. The patient subsequently asked his medical oncologist for lethal medication prescription under the law. The medical oncologist contacted the expert witness and asked him to be the consulting physician as required by ODDA. He refused. Nevertheless, according to the witness, a second opinion was sought and obtained elsewhere and the patient subsequently died from a "lethal overdose prescribed by the medical oncologist" (affidavit). This experience rent asunder the witness' relationship with the medical oncologist:

> The medical oncologist who prescribed a lethal dose of medication for my patient had known and been treating him for only a few weeks. The professional relationship between the medical oncologist and myself was destroyed. I no longer trusted her and have never referred a patient to her again. Based on this experience, I believe that the tragedy of the system in Oregon is that instead of doing the right thing, which is to provide excellent care, patients' lives are being

> cut short by physicians who are not addressing the issues underlying patient suicidality at the end of life (affidavit).

Note how the witness pointedly referred to how medical oncologist had known his patient for only a few weeks, in contrast to the ten-year relationship he had cultivated. The witness' description was meant to convey not only that PAD was not the right intervention for the patient but also a sense of betrayal and disappointment rooted in the perceived inadequacy of care provided by the medical oncologist. This point was made all the more revealing when he added that in "my experience, *when I take the time and connect with my patient*, I learn what is important to them, what makes their life have meaning, and what is underlying their request for suicide" (emphases added, affidavit).

Canada also characterized PAD as a medical practice borne out of professional inexpertise in palliative care. The fields of end-of-life care in the permissive jurisdictions were perceived by Canada to be a zero-sum game whereby the legal availability of PAD had caused a concomitant reduction in the quality of palliative care delivered there. This negative impact could be observed at both the individual (i.e., skills and knowledge) and systemic (i.e., support given to palliative care as a speciality) levels. A palliative care physician testifying for Canada took to the witness stand and recounted two incidents from his experience working and teaching at a Swiss university hospital. He had organized a palliative care workshop that was sparsely attended. He had also designed an optional palliative care course that received poor uptake by the physicians at the hospital. When he inquired into the reason for the poor reception of the workshop and the course, he was informed that "there was someone who said, 'well, I guess I don't have to do this if there is access to assisted suicide'" (trial transcript). Canada further emphasized that what was needed in caring for patients at the end of life was not just any type of palliative care but 'specialist palliative care.' Canada relied heavily on many narratives of professionals' experience in permissive jurisdictions to construct PAD as a medical practice delivered by uncaring, unskillful physicians within a structural environment in which palliative care had been devalued because of the legal availability of PAD.

The claimants, on the other hand, constructed a picture of PAD as practiced not by incompetent physicians but by empathetic, compassionate professionals. During her cross-examination, a researcher from Oregon expounded on one study of Oregon psychiatrists' attitudes towards PAS. She explained that the study revealed that those psychiatrists supportive of the law "actually wanted – potentially wanted assisted suicide for themselves" (trial transcript). Three-quarters of the psychiatrists sampled in the study stated that they would like the option of PAS for themselves; these were the psychiatrists who were more likely to support Oregon Death with Dignity Act and to feel that they could determine the patient's needs. "So it may be that they were more empathetic to the patients that they could understand how it was possible to want assisted suicide", the witness concluded. In this way, PAD could be seen to be an expression of a professional ethics of care.

With regard to palliative care in permissive jurisdictions, a palliative care physician described Belgium as having a different "philosophy" in which there was a lower "threshold of access to palliative care" for patients and in which palliative care competency was dispersed more widely throughout the healthcare system rather than concentrated within a select group of professionals (interviewee 11). So while "the professional technicality of that care is not the same as a very renowned and top palliative care services like at McGill, you know the tradition of Balfour Mount and all that," patients in permissive jurisdiction were still receiving good palliative care as "part of normal medical care."[9] As stated by a Dutch bioethicist, "[s]o we want a general physician to be able to perform palliative care; we want an oncologist to be able to perform palliative care; we want a nursing home physician to be able to give good palliative care" (interviewee 5). The claimants thus emphasized the importance of primary, rather than, specialist palliative care in end-of-life care.

Some witnesses for the claimants went so far as to argue that palliative care had improved in permissive jurisdictions *because of* legalization. The improvement, they claimed, had come about paradoxically through the antagonistic stance taken by many of those in the palliative care community. Wright and colleagues (2015) have observed that many in the palliative care community are opposed to the ethics of PAD. As one witness from Washington state said, "there is this philosophy that many of these [palliative care] providers have, whether right or wrong, that they believe that if they do a better job at managing their, palliating their patients' pain and symptoms, that patients won't choose the option of 'death with dignity'" (interviewee 6). He believed that these palliative care providers had allowed their own moral-political opposition to "color their professional judgment," but such opposition had actually resulted in "more aggressive palliative care and better symptom management." In other words, healthcare providers made conscious efforts to provide better palliative care with the hope that patients would not resort to PAD; such efforts were seen to have inadvertently resulted in the overall improvement of end-of-life care in permissive jurisdictions. The claimants thus constructed PAD as a practice that could exist alongside good palliative care.

Regulating Physician-Assisted Dying

In the preceding two sections, we have shown how participants' engagement with the evidence evinced competing understandings of the patients and the physicians implicated in PAD. In this section, we discuss divergent understandings of PAD as an institutional product. Participants used evidence from permissive jurisdictions to evaluate the overall functioning of the regimes and to scrutinise the relationship of different players within them. As mentioned previously, all of the PAD regimes' data rely on *a posteriori* reporting by physicians. This feature of the regimes, for Canada, constituted a systemic flaw through which problematic abuse could be made to disappear. An anti-euthanasia group, the Euthanasia Prevention Coalition (EPC), along with its provincial affiliate the EPC British Columbia, intervened in support of Canada's position. The executive director of EPC stated that while "the official reports of euthanasia deaths for the most part appear to be reasonably safe" (interviewee 4), he would not adopt the conclusion that the regimes had not inflicted any harm. He asked rhetorically, "where did the data come from? The data came from the reports from the doctors who did the euthanasia," implying that physicians might be reporting that they had followed the due care requirements when, in fact, they had not.

Canada contended, as well, that the official data might not account for all cases of PAD. We had discussed earlier the nationwide studies on medical end-of-life decisions in Belgium and the Netherlands. Referencing this research, the EPC stated that the "most staggering fact remains that after 9 years of legalized euthanasia in the Netherlands, 23% of deaths continue to go unreported and up to 47% go unreported in Belgium" (factum). The official data were, therefore, conceptualized as partial in both senses of the word: biased, because it may be masking abuse by physicians, and incomplete, because they represented only a sliver of the reality of PAD.

State authorities in particular were deemed by some of Canada's expert witnesses to be complicit in what they saw as physicians' abuse of the law. As previously discussed, the nationwide studies in medical end-of-life decisions in the Netherlands and Belgium enabled researchers to 'uncover' the practice of Life-Ending Act Without Explicit Request of Patient (LAWER). Canada interpreted LAWER to be non-voluntary euthanasia and therefore evidence of a slippery slope towards the countenance of a morally suspect practice that could put the vulnerable at risk. When asked by the trial judge why he thought LAWER could have taken place in the Netherlands, a psychiatrist testifying for Canada replied:

> We have certain guidelines but they're not enforced so the net result is people get away with murder. It encourages them to do it. The guidelines don't help because they just see that nothing can happen. Nobody regulates it in a strong way (trial transcript).

For this participant, the regulation that resulted from legalization actually provided a legal fig leaf to those physicians who "get away with murder [i.e., LAWER]." Moreover, he saw the state as failing to enforce the regulation, further encouraging physicians' abuse of the law. Here, Canada used one body of evidence to question the credibility and validity of the government data, thereby questioning the moral integrity of the regimes. In their final submission to the SCC, Canada stated that "paper safeguards are only strong as the human hands that carry them out." In arguing that the official data were partial and emphasizing what they saw to be the failing of the state, Canada cast aspersions on the "human hands" of the regimes, constructing PAD to be the sum of the regimes' fallible parts.

The claimants, on the other hand, emphasized PAD as the product of a regime in which in the participants were conceptualized as interlocking parts and in which individual actions must be seen as dependent on and consequential to the actions of other players within the regime. When discussing the criticism that the self-reporting feature of the Dutch regime could be masking evidence of abuse, a Dutch bioethicist pointed out that the regime did not rely exclusively on self-reporting by the attending physician:

> [The Dutch regime] relies on self-reporting, but no, not only, and not exclusively because a second physician has to visit the patient and talk with the patient independently, has to write his or her own report, and it's not just the self-report. You also have to send in the complete medical file of your patient, and of course everything can be forged, but I don't believe that any physician would make such a 'Truman Show,' so the, if there are any inconsistencies, then the assessment committee will be able to find them (interviewee 5).

For this participant then the regulation of PAD occurs at multiple locations involving multiple actors who function in essence as sentries overseeing the actions of other actors. One of the claimants' expert witnesses from Oregon expressed just this point when he said that: "You would think, after more than a decade and a half, at least somebody would come forward and say that this was amiss, this was wrong, this was terrible" (interviewee 8).

DISCUSSION: MAKING PHYSICIAN-ASSISTED DYING CULTURALLY APPROPRIATE

We have shown the roles that new knowledge from permissive jurisdictions played in the legalization debate in Canada. Legalization of PAD produces new subjects (PAD patients and other actors implicated in the regime) and, at the same time, produces a structure under which a practice is enacted. These subjects and the legalized medical practices become amenable to observation and inquiry by different actors (state officials, researchers, physicians) giving rise to new forms of knowledge about PAD. The new knowledge may then be taken up by the stakeholders as 'evidence' in the debate over legalization in other empirical settings in multiple ways and for various purposes. The proponents in particular used these new data to reopen the legal debate on PAD that had previously been closed by *Rodriguez*. Their success has implications for other closed legal debates on PAD elsewhere.

Our analysis contributes to studies on how the meanings of PAD have been constructed over time. Research from this body of literature has shown that the meaning of PAD is historically contingent (Lavi, 2007; Van Hooff, 2004). In this article, we show how knowledge that has emerged only in the past twenty years can be deployed as new epistemic resources through which stakeholders construct competing contemporary understandings of the reality of PAD. Court proceedings are an excellent empirical site for observing such process of reality construction (Scheffer, 2007). The adversarial nature of the legal process lends itself to the construction and deconstruction of facts, turning court trials into what Lynch (1998, 830) has called "a veritable sociology of knowledge machine." We have observed just such a process in *Carter*; our analysis shows the actors in the case engaged with expert evidence from permissive jurisdictions around three central tensions: 1) whether patients who seek PAD are suicidal or rational; 2) whether physicians who enact PAD are competent in end-of-life care; and 3) whether structures of oversight can safely regulate PAD.

The ostensible purpose of the proponents' use of expert evidence was to make the legal point that "a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error" (Carter v. Canada (Attorney General) 2015 SCC 5, 468 N.R. 1, (Can.), 65). They succeeded in persuading the courts on this point.[10] A full accounting of why the claimants succeeded would need to take into account their argument on the evolution of Canadian legal principles, which is beyond the scope of this article. Their success has important implications, however, for our collective understanding of PAD. The court is, after all, a regime of truth production, a foundational institution in society that is able to make publicly legitimized authoritative claims to the production of 'true' knowledge and facts on a phenomenon (Latour, 2010). We suggest that the courts' acceptance of the proponents' claims has contributed to the production and reproduction of a specific cultural script that renders deaths from PAD 'culturally appropriate.'

The notion of 'culturally appropriate death' was first elaborated by Timmermans (2005) in his study of medical death experts. Timmermans shows how in cases of "apparently senseless deaths" (2005, 995) – such as those in sudden deaths – medical experts perform a variety of activities to render those deaths explainable and meaningful to relatives and other actors, activities that he terms 'death brokering.' In other words, death brokering renders the deaths of patients culturally appropriate. Pertinent to our analysis is Timmermans' insight that a culturally appropriate death relies on cultural scripts imbuing death with positive meanings that resonate with widely shared societal values and norms (see also Seale, 1998). Similarly, we argue that the ways in which the proponents of legalization used the knowledge from permissive jurisdictions as new epistemic resources have contributed to the production and reproduction of a specific cultural script for what it means to be dying by way of PAD. In this script, deaths via PAD are made culturally appropriate because patients are rational and thus not suicidal; a patient’s request is part and parcel of his/her personal values system; the practice is carried out by caring, empathic physicians within a structural context where palliative care can thrive alongside PAD; and the practice is produced through a reliable regime where the involvement of multiple actors is seen to constitute the safeguards.

Our methodologically symmetrical approach to the data has allowed us to see as well the opponents’ constructions of PAD. We have deliberately included an analysis of the opponents’ constructions because “the believability of social constructions … depends on what the [construction] expels to the outside. In this sense, social constructions are, at once, constituted and haunted by what they exclude” (Pfohl, 2008, 646). Prior to the emergence and wide circulation of the new knowledge from permissive jurisdictions, many commentators had constructed the narrative of PAD as one in which patients at the end of life would be driven to PAD because of untreated pain or depression (e.g., Cherny, 1996; Walker, 2003; Wolf, 1997). The history of Nazi physicians’ abuse has also imbued euthanasia with a lasting eugenics connotation (Dowbiggin, 2003). Indeed, these meanings were reproduced in Canada’s claims throughout *Carter* whereby patients were seen as suicidal; the practice was born of professional inexpertise in end-of-life care; and where abuse could be made to disappear with the complicit action of the state. Nonetheless, these constructions ultimately failed in achieving the hybrid legal-scientific status of ‘facts’ and were expelled ‘to the outside’ by the courts. Our analysis thus accords with the sociolegal literature that argues a change in the meaning of the contested phenomenon is a necessary precondition to social change (Beckett & Hoffman, 2005). The success of the proponents in the court was a crucial step towards the larger social change of PAD.

The proponents’ efforts at legalization, however, did not unfold in a landscape of their own making. As Beckett and Hoffman (2005) have argued, cultural meanings are not infinitely plastic. Proponents had to learn to invoke existing dominant positive categories and symbols to persuade their audience. The proponents’ script of PAD resonates morally and emotionally with the “increasing individualism of modern values” (Deflem, 2008, 199). They also found resonance with the positive values of the postmodern good death that include, among others, privacy, dignity, independence, personal growth, and informed choice (Walter, 1994). Medicine, too, has come to occupy a central place in the contemporary death and dying experience; as such, there is very little room to create narratives of death and dying outside of the biomedical context (Seymour, 2007). More specifically, the proponents could not dispense with the institution and ethos of palliative care that have come to dominate end-of-life care (Livne, 2014). Thus, the proponents needed to enfold palliative care into their script of PAD in order to make it culturally appropriate.

Carter v. Canada is but one in a series of recent attempts to decriminalize and legalize PAD. In May 2015, the High Court of New Zealand heard a case brought by a woman against the country’s legal prohibitions on PAD. Johnston (2015) observes that the New Zealand case has been buoyed by the success of the proponents of legalization in

Carter. In North America, the governor of California signed the *End of Life Option Act* on 5 October 2015 legalizing PAS in that state. It seems to us that the legalization effort will continue unabated in many different parts of the Western world in the foreseeable future. Of course, not all of these efforts have been or will be successful. The Irish Supreme Court, for example, recently upheld the Criminal Law prohibitions on assisted suicide ([2013] IESC 19). Future observers would do well to look closely at the variations of the ways in which data and knowledge from permissive jurisdictions are used by stakeholders to construct various contemporary meanings in both successful and failed legalization debates.

NOTES

[1] *Carter* began in the British Columbia Supreme Court in 2011 where Smith J. found for the plaintiffs, a decision that was later overturned by the British Columbia Court of Appeal in 2013. The SCC granted claimants leave to appeal and heard the case on 15 October 2014. In the aftermath of the ruling, the federal government was given 12 months to amend the Criminal Code before the impugned prohibitions become null and void in the context of PAD.

[2] This is not to say that the debate on PAD did not continue in other spheres of Canadian society. Since 1993, six private members' bills to legalize PAD had been introduced in Parliament.

[3] These jurisdictions are as follows: The American states of Oregon, Washington, Montana, Vermont, New Mexico and California, the Northern Territory of Australia (later overturned by Canberra), Colombia, the Netherlands, Belgium, Luxembourg, and Switzerland.

[4] We recognize differences in the processes that produced the legal, documentary data and the interview data as well as the different types of sociological claims that could be made with each type of data. In this study, however, the in-depth interviewing was designed from the outset to 'speak' directly to the legal data. The interview guide for each participant was tailored according to that participant's legal data (i.e., the participant's factum, affidavit, or examination transcript). The interviews thus provided not only depth and nuance to the legal data, but another discursive opportunity for the participants to construct the reality of PAD in particular ways.

[5] Only PAS is legal in Oregon and Washington. Colombia has euthanasia only. In Switzerland, assisting a person to commit suicide is not a crime so long as it is done for unselfish reasons. The Netherlands and Luxembourg have legalized both euthanasia and PAS. In Belgium, while the law explicitly mentions euthanasia only, the oversight body has allowed for PAS.

[6] To stay close to the data, we use the term 'Canada' here to refer to the opponents (i.e., the Attorney General of Canada along with its witnesses and interveners supporting its position).

[7] 'Claimants' refer to the proponents (i.e., the plaintiffs along with their witnesses and interveners supporting their position).

[8] This is not to imply that our study participants did not make distinctions between euthanasia and PAS. All of the actors involved in the case recognized the practical and policy distinctions between euthanasia and PAS.

[9] Balfour Mount is widely acknowledged to be a palliative care pioneer in North America (Youk, 2004). In 1974, he established one of the first palliative care units in Canada at the Royal Victoria Hospital, part of McGill University Health Centre in Montreal. In Canada, palliative care exists as an official sub-specialty of medicine.

[10] In their decision, the SCC Justices agreed with the findings of Smith J., the trial judge, stating that she "made no palpable and overriding error in concluding, on the basis of evidence from scientists, medical practitioners and others who are familiar with end-of-life decision-making in Canada and abroad, that a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error" [Carter v. Canada (Attorney General) 2015 SCC 5, 468 N.R. 1, (Can.), 10].

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CHAPTER 3

SUFFERING AND MEDICALIZATION AT THE END OF LIFE: THE CASE OF PHYSICIAN-ASSISTED DYING

ABSTRACT:

‘Suffering’ is a central discursive trope for the right-to-die movement. In this article, we ask how proponents of physician-assisted dying (PAD) articulate suffering with the role of medicine at the end of life within the context of a decriminalization and legalization debate. We draw upon empirical data from our study of *Carter v. Canada*, the landmark court case that decriminalized PAD in Canada in 2015. We conducted in-depth interviews with 42 key participants of the case and collected over 4000 pages of legal documents generated by the case. In our analysis of the data, we show the different ways proponents construct relationships between suffering, mainstream curative medicine, palliative care, and assisted dying. Proponents see curative medicine as complicit in the production of suffering at the end of life; they lament a cultural context wherein life-prolongation is the moral imperative of physicians who are paternalistic and death-denying. Proponents further limit palliative care’s ability to alleviate suffering at the end of life and even go so far as to claim that in some instances, palliative care produces suffering. Proponents’ articulation of suffering with both mainstream medicine and palliative care might suggest an outright rejection of a place for medicine at the end of life. We further find, however, that proponents insist on the involvement of physicians in assisted dying. Proponents emphasize how a request for PAD can set in motion an interactive therapeutic process that alleviates suffering at the end of life. We argue that the proponents’ articulation of suffering with the role of medicine at the end of life should be understood as a discourse through which one configuration of end-of-life care comes to be accepted and another rejected, a discourse that ultimately does not challenge, but makes productive use of the larger framework of the medicalization of dying.

KEYWORDS: Canada; physician-assisted dying; euthanasia; assisted suicide; palliative care; end-of-life care; suffering; medicalization of dying.

> This is a momentous occasion, for my clients, for society, for this court. This case quite simply concerns matters of life and death. It may require the court…to determine if the state has the right to require family members, our friends, ourselves to endure intolerable suffering as a result of a medical condition when that suffering is worse than life itself.
>
> Joseph Arvay, At the Supreme Court of Canada, October 15, 2014

INTRODUCTION

Lead counsel for the claimants in *Carter v. Canada*, Joseph Arvay, uttered the above as part of his opening statement to the Supreme Court of Canada (SCC). *Carter* was landmark litigation that challenged the constitutionality of the Criminal Code prohibitions on physician-assisted dying (PAD; euthanasia and physician-assisted suicide). Less than four months after the hearing, the Justices released a unanimous decision striking down the prohibitions on PAD, giving the federal government a limited window of time to revise the law. On June 17, 2016, the Parliament passed legislation on PAD. Canada is now one of a growing number of countries in which the practice is legal.

Arvay's statement above highlights the centrality of suffering as a discursive trope in the right-to-die movement. Indeed, Scherer and Simon (1999) have identified 'suffering' along with 'autonomy' to be the primary social movement frames used by the proponents of PAD. Considerations of suffering in the right-to-die movement, however, cannot be divorced from discussions about the role and place of medicine at the end of life. As Lavi (2001) argues, the right-to-die movement must be properly seen "in the medical context in which it arises and primarily as a solution to the problem of pain in dying" (p. 138). Implicit, too, in Arvay's statement is an indictment on medicine's failure to adequately address suffering. This article therefore aims to investigate how proponents articulate suffering with the role of medicine, particularly in the end-of-life context. We use 'articulate' to mean the process of forming discursive linkages between two different entities or concepts. In other words, how do the proponents construct the relationship between suffering and medical interventions at the end of life? This requires us to grapple with such questions as: What do the proponents identify as the primary causes of suffering at the end of life? In what ways do they suggest medicine, including palliative care, is (un)successful in addressing suffering? In the context of PAD, how do the proponents conceive the role of medicine in addressing suffering?

In order to answer these questions, we draw upon a set of original, empirical data from our investigation of *Carter v. Canada.* We begin by describing *Carter* in greater detail. We then describe two social phenomena that others have identified as transformative of the contemporary dying experience: the increasing use of life-extending interventions in mainstream curative medicine and the emergence and rise of palliative care as the paradigmatic end-of-life care modality. This description serves two purposes: to provide readers with necessary context for many claims advanced by *Carter*'s proponents and to serve as a basis for discussion of our empirical data in the last section of the article. We then proceed to describe our study methods. In our reporting of results, we find that proponents see curative medicine as complicit in the production of suffering at the end of life. Proponents draw limits around the ability of palliative care to relieve suffering; they further contend that in some instances, palliative care can actually produce additional suffering. At the same time, proponents insist that physicians must be involved in any legal regime of assisted dying. Thus, we also find that proponents emphasize how a request for PAD can set in motion an interactive medical process that has the potential to alleviate suffering at the end of life. In the discussion section, we argue that proponents' articulation of suffering with the role of medicine constitutes a discourse through which different configurations of end-of-life care come to be rejected or accepted *within the larger framework of the medicalization of dying*.

BACKGROUND

Contextualising Carter v. Canada

Political efforts to legalize PAD date back to the late nineteenth century (Dowbiggin, 2002; Lavi, 2007). It was not until 1997, however, that the first law on physician-assisted suicide (PAS) went into effect, in Oregon. Thereafter, a quick succession of other medico-legal regimes appeared, including Netherlands in 2002 and recently California in December 2015. Although euthanasia is an ancient topic (Van Hooff, 2004), PAD as a medicolegal practice accessible to the public at large is a relatively recent phenomenon. There are now 13 jurisdictions, including Canada, that have decriminalized or legalized PAD.

Carter v. Canada is a watershed moment in the history of the global right-to-die movement. With *Carter,* Canada became only the second country in the world, after Colombia, to have allowed for PAD on constitutional grounds. Moreover, *Carter* decriminalized not only PAS but also, for the first time in North America, euthanasia. The case began in the Supreme Court of British Columbia (the province's court of first instance) in 2011. It was then heard at the British Columbia Court of Appeal in 2012, and finally the country's highest court in 2014. The claimants included Lee Carter and her husband Hollis Johnson, Gloria Taylor, William Shoichet, and the British Columbia Civil Liberties Association (BCCLA). Carter and Johnson had accompanied Carter's mother to die at an assisted suicide clinic in Switzerland the previous year, an event that they made public immediately afterward. Taylor was a woman with

Amyotrophic Lateral Sclerosis (ALS) and Shoichet was a family physician. The diversity of the claimants was meant to reflect the diversity of persons with stakes in the legalization of PAD.

The *Carter* claimants challenged the Canadian Criminal Code prohibitions on assisting in another person's suicide and on consenting to one's death. The claimants' legal arguments essentially advanced along the lines of autonomy and equality. The autonomy argument stated that ill patients ought to have the right to seek PAD in order to control the manner and time of their own dying. The equality argument stated that since attempting suicide was not a crime, the ban on assisting suicide had the discriminatory effect of preventing disabled persons incapable of suicide from taking their own lives. The SCC eventually agreed with the claimants' autonomy argument and having done so, found it unnecessary to adjudicate the matter in terms of equality (for more details on the ruling, see Karsoho, 2015).

The right-to-die movement, like other social movements, developed within a socio-historical context that both enabled and constrained what could be accomplished by the proponents. In the rest of the section, we discuss in brief two important social phenomena that have radically transformed the dying experience in contemporary times: the growing use of life-prolonging technologies in mainstream medicine and the emergence of palliative care. Many authors see these phenomena as constituting the larger process of the medicalization of dying and intersecting with the right-to-die movement in significant ways.

Mainstream Curative Medicine and The Extension of Life

Mainstream curative medicine is now ever more reliant on the sciences and technologies (Clarke et al., 2003). For persons nearing the end of life, such "technoscientization of biomedical practices" (Clarke et al., 2010) manifests itself in the normalization and routinization of life-extending technologies (Kaufman et al., 2004; Shim et al., 2006). These life-prolonging technologies have created new forms of dying (e.g., neurovegatative state) and at the same time remade the moral frameworks at the end of life (Kaufman, 2005; Kaufman & Morgan, 2005).

In Kaufman's (2015) incisive ethnography on "ordinary medicine," she notes how the biomedical research industry is producing evidence of effective therapies at historically unprecedented rate. Many of these therapies (e.g., implantable cardiac defibrillator) were originally intended as last resort options. Once insurable, however, they become standard care and "ethically necessary and therefore difficult, if not impossible, for physicians, patients, and families to refuse" (Kaufman, 2015, 7). Indeed, refusing these potentially life-prolonging therapies seems irrational or even downright morally wrong in a cultural context in which death is seen as bad. The problem then is that "few know when that line between life-giving therapies and too much treatment is about to be crossed...the widespread lament about where that line is located and what to do about it grows ever louder" (Kaufman, 2015, 2). The use of life-extending technologies reproduces and, at the same time, is made possible by the organising principle of mainstream medicine: the (mistaken) belief that life can be prolonged more or less indefinitely through medical interventions, a pervasive cultural ideology that Dumas and Turner (2007; 2013) call "prolongevism" and which they view as producing more harms than benefits to persons at the end of life.

The Rise of Palliative Care

Public concerns about the medical care of the dying in the developed world began to surface in the 1950s when systematic studies revealed the neglect of dying patients and under-treatment of their symptoms (Clark, 2002; Clark, 2007). These concerns about care of the dying were taken up most notably by Cicely Saunders, who is widely acknowledged to be the founder of the modern hospice movement. Saunders founded the first modern hospice, St. Christopher's Hospice, in London, UK, in 1967 (Saunders, 2000). The success of St. Christopher's, together with Saunders' prolific writing contributed to the development of "a new approach to the care of dying people which would harness together medical innovation in pain and symptom management with wider concerns for the practical and social needs of patients and families, as well as responsiveness to spiritual matters" (Clark & Seymour, 1999, 72). One of Saunders' most important intellectual contributions to medical knowledge and practice is the concept of 'total pain,' which argues that suffering is irreducible to physical pain and must be understood in its multiple dimensions: physical, psychological, social, and spiritual. In order to relieve suffering, care for the dying must therefore be similarly holistic (Clark, 1999).

The modern hospice movement quickly gained international following. Balfour Mount, a Montreal urologist, coined and brought the term 'palliative care' into wide usage, preferring its use to 'hospice' because in French the word 'hospice' referred to almshouse (a house for the poor, not the dying) (Lewis, 2007). Knowledge and practice of palliative care quickly spread to other countries such that 115 of the world's 234 countries now have one or more palliative care services (Clark, 2007). Palliative care, however, has not provided equal benefits to all patients. The development of palliative care is deeply rooted in oncology, "which has shaped the conceptual model of palliative care, produced some of its major leaders and innovators, and provided a population of patients with the obvious potential to benefit from a new approach to the management of those with advanced disease" (Clark, 2007:, 430). This means that cancer patients are more likely than patients with other terminal illnesses to benefit from palliative care (Clark, 2007).

The ethos of palliative care is typically portrayed as antagonistic to the idea of PAD as an ethical EOLC practice (Bernheim et al., 2008). Hermsen and ten Have (2002) analyze how PAD is discussed in palliative care journals and found that the “majority of the examined articles do not consider euthanasia as an ethically legitimate act in the context of palliative care” (p. 524). Wright et al. (2015) analyze the representation of physicians’ perspectives on PAD in the Canadian print media and identify a palliative care advocacy discourse whereby physicians who self-identify as part of the palliative care community voice a strong and consistent message of opposition to PAD. Reasons given for opposing PAD include, but are not limited to, the ethical principle of respect for life, the ability of palliative care interventions to address suffering, and concern about the diversion of resources away from palliative care.

The Medicalization of Dying

The two phenomena just described attest to the ways in which dying in Western societies has changed radically since the Middle Ages. There are, of course, other processes (e.g., demographic transition) that underlie the changes and these have been explored elsewhere (see Ariès, 1981; Kellehear, 2007; Seale, 1998; Walter, 1994). Starting in the mid-twentieth century, however, changes in dying are best characterised as medicalization (Howarth, 2007). As Broom (2015, 6) argues, “[e]ssentially, dying from medical illness was gradually transformed over the course of the twentieth century into a *medical challenge* not just an *existential moment*...Increasingly medicalized, dying was drawn into various institutions and viewed as a site of medical expertise and professional skill” (emphases in the original).

The medicalization of dying is immediately self-evident when one considers the use of life-prolonging interventions in mainstream curative medicine. But what about palliative care? Some see palliative care as a pointed critique on the medicalization of dying. McNamara (2001) argues that palliative care "has the potential to disrupt the medicalization of death" (76) and "has served as a symbolic critique of how dying people are managed in other medical settings" (121). Others, however, see palliative care as contributing to the medicalization of dying. Broom (2015, 12), for example, views palliative care as part of the overall trend of the medicalization of dying: "The medicalization of dying – via hospice and specialist palliative care … had the potential to reinforce the cultural dispositions toward death, separating those who are dying from the community and their families, and further concealing this important point in the life course." It is, of course, possible for palliative care to be a medicalizing and, at the same time, demedicalizing force. Indeed, Syme and Bruce (2009, 20) argue for a view of palliative care as a "social movement that *augmented and opposed* mainstream curative medicine as the hegemonic model of care" (emphases added). Such view is supported by a historical reading of Saunders' original intentions: according to Clark and Seymour (1999, 64), Saunders actually wanted to "*improve and extend* medical care at the end of life. The debate of course was around the precise form which this medicine should take" (emphases in the original).

The term 'end-of-life care' (EOLC) is best understood as a configuration of healthcare resources (i.e., people, practices, and technologies) mobilized at the last phase of a person's life. While palliative care has become the paradigmatic EOLC modality today (Livne, 2014), it does not have a complete monopoly over EOLC. According to Connelly (1998), there exist two dominant logics in EOLC: on the one hand, there is the 'dying well' path in medicine, as represented, practiced, and promoted by palliative care professionals. On the other hand, there is still the traditional 'life-saving' path of medicine whereby treatment is directed at curing the patient's disease; the goal is always to prolong life and comfort care is secondary to this goal. For most dying individuals, then, the medicalization of dying has come to mean that their last days of life are strongly shaped by either or the interplay of these two EOLC logics. For proponents of PAD, the medicalization of dying serves as *the platform from which* to argue the moral imperative of new options in EOLC. In the results section, we will show how participants in *Carter v. Canada* engaged both EOLC logics (the 'dying well' path and the 'life-saving' path) as inadequate in addressing, and in some cases even perpetuating, the fundamental problem of suffering in dying.

MATERIALS AND METHODS

Carter v. Canada represents for us a "critical case" (Flyvbjerg, 2001) through which we can fruitfully investigate how PAD proponents articulate suffering with the role of medicine at the end of life. A critical case is not the same as a representative or a typical case; instead it is a case that is rich in information. Indeed, so extensive was the scope of evidence and actors involved in *Carter* that an Irish court in a subsequent PAD litigation noted that the review conducted by the Canadian trial judge was "enormously detailed and comprehensive" [Fleming v. Ireland. (2013) IESC 19 (BAILII)]. By the time *Carter* reached the SCC, 97 witnesses and 26 interveners, along with the claimants, their legal counsels, and the Crown Counsels had participated in the case. The expert witnesses called on by the claimants and the government hailed from 7 different countries. The selection of a critical case is important if the goal of analysis is to generalize not to other cases (i.e., statistical generalisation) but to theory (Ruddin, 2006), as is our intent here.

Prior to data collection, the study received Institutional Review Board approval from McGill University. The data we analyse consist of all of the legal artefacts generated by the case (i.e., affidavits, trial transcripts, factums, court decisions), all amounting to over 4,000 pages of texts, and in-depth interviews with key participants in the case. The first and third authors also attended the SCC hearing on October 15, 2014 and took observational notes. Our selection of interviews with participants is predicated upon the insight that not all actors are created equal in a controversy (Venturini, 2010); we therefore selected only those actors with the most impact in the case: the claimants, interveners, and witnesses whose opinions were cited by the judges in the case. In the case of the witnesses, for each participant who did not respond, declined, or was lost to follow up, we made sure to recruit another participant who could speak to similar issues. Our recruitment process resulted in 42 interviews. The interviews were designed to 'speak' directly to the legal data; the interview guide for each participant was tailored according to that participant's legal documents. Our participants were interviewed either in person or over Skype. All interviews were audio recorded and transcribed. Informed consent, either written or verbal, was obtained from every participant. For those participants who chose to remain anonymous, we identify only the data source (e.g., interview, trial transcript). Those we name in this article have given us permission at the time of interview to identify them. Data collection for this article spanned 21 months from June 2013 to March 2015.

Analysis proceeded along an iterative process involving coding, memo writing, and literature review. We began by uploading all of the documents to Atlas.ti^{TM}. Karsoho then coded all of the documents both deductively, using themes derived from the literature, and inductively for emergent themes. For this article, our analysis was initially guided by an analytical interest in the role of medicine in the debate over legalization of PAD. Karsoho reviewed all of the codes pertaining to this issue; during this process, 'medicalization' and 'suffering' emerged as "core categories" (Strauss & Corbin, 1998). Further elucidation of the relationship between these categories occurred through memo writing and consultation with the literature. This initial analysis was then presented to the co-authors for multiple rounds of further analysis and clarification.

Our analytical approach to the data is guided by insights from studies of discourse in sociology of knowledge. Following Potter (1996), we understand discourse to be *talk and text in action*. Discourse here is understood to be part of a broader repertoire of human actions used to *accomplish something*. In order to understand how talk and text do things, we have to consider their "deployment in specific interactions and the nature of those interactions (Potter, 1996, 180)." This understanding of discourse guides our analysis in two interrelated ways. First, we interrogate the *practical nature* of actors' text and talk, rather than its truth value. That is, we are constantly asking, 'what are our study participants attempting to do here?' What legal, moral, or political aims are advanced by describing suffering in particular ways? Second, we treat actors' discourse not as a resource but as a topic (Gilbert and Mulkay, 1984). In other words, we do not take the words of our participants to be 'true' but attend to the ways in which meaning is produced and to what effects. Therefore, proceeding from the assumption that language is “used to do things; it is a medium of action” (Potter, 1996, 11) allows us to be mindful of the broader legal context in which our data is produced. We approach the data not as evidence of a ‘true’ or ‘real’ perspective on suffering and the role of medicine but rather as a strategic deployment of language by the participants to advance specific agenda.

In this article, we focus and present data on the proponents’ discourse; however, their discourse was necessarily constructed vis-à-vis the opponents’. Thus, in a few places, we present data from the opponents’ discourse to provide greater clarity for readers. Our use of the term ‘proponents’ or ‘opponents’ is not intended to elide the diversity of opinions and positions within each ‘side’ in the debate. We recognize that our study participants may differ in the strength of their support for the claimants or the government. By proponents, we mean the claimants and all of the actors (interveners, witnesses) who are strategically enrolled by the claimants to advance their case for decriminalization. Opponents refer to all of the actors on the opposing side.

RESULTS

Proponents’ discursive articulation of suffering occurs throughout the data. Expressions of suffering are most common amongst – although not limited to – the claimants, lay affiants, and those expert witnesses who professionally identify as physicians. Lay affiants often speak about either their own illness or having witnessed their loved ones die, using such adjectives as “horrific,” “heartbreaking,” and “torturous” to describe their experiences. Physicians, on the other hand, often speak of their professional experience caring for patients with intractable suffering.

There is an overwhelming consensus among the proponents that only suffering arising from medically diagnosable conditions could ever justify the need for PAD, the sole exception being a representative from Right to Die Canada who told us during interview that she would also accept suffering from a non-medical condition as a justification (e.g., tiredness of life). Further, mental illness is discussed less as a source of primary suffering at the end of life, and more as a potential source of interference with a person's ability to make a clear and rational decision around assisted dying. During the SCC hearing, for example, Arvay suggests that any existing mental co-morbidities (e.g., depression in a context of cancer) be treated before a patient be granted access to PAD. Finally, while intractable (physical) suffering could occur at any point in the illness trajectory, proponents emphasize suffering that occurs in the last phase of life.

Having described how suffering appears in our data, we now turn to the ways in which suffering is linked by proponents to the practices of mainstream curative medicine, palliative care, and assisted dying.

The Complicity of Mainstream Curative Medicine

Proponents evince an awareness of the larger biomedical context in which the contemporary dying experience is embedded: that medicine plays an increasingly important role at the end of life. Citing figures from Belgium, one EOLC researcher notes that medical end-of-life decisions are now implicated in half of all deaths in the country. According to this researcher, this means that "doctors are more and more responsible for decisions that have huge implications on the quality of life of the patients" (interview, Deliens).

While proponents acknowledge that “medicalization” prolongs life, it does not come without concomitant costs. In fact, proponents argue that it is the medical efforts to prolong life that render the dying experience difficult. Leslie Laforest, a lay witness with anal cancer, describes what she sees to be effects of the litany of medications that are needed to sustain life in the context of a terminal illness:

> In order for people to maintain life in terminal illnesses, they very often have to be on wretched volumes of drugs that make them sick, that make them queasy, that make them extraordinarily sad, that sink them into a depression regardless. So then you’re on this whole super highway of trying to balance the depressants; the drugs that they have to have to keep them alive is giving them, needs to be counteracted with drugs to try and lift their spirits like with [antidepressant].
>
> (Interview.)

For Laforest, the interventions necessary to prolong life may be causing harms that then need to be counteracted with more medications. She pointedly views the cascade of interventions and suffering as “ridiculous.” Medicine, in the words of the proponents, has made life worse for terminally ill patients.

To be sure, proponents understand that the severity of suffering is, to a large extent, determined by the nature of the illness itself. In many of the affidavits, seemingly exhaustive lists of symptoms of various illnesses are presented, enumerated by the proponents to showcase the enormity of suffering that terminally ill patients experience. In describing these illnesses, they also express overwhelming moral disapprobation towards the culture of curative medicine. In particular, they highlight the inherent life-prolonging imperative of mainstream curative medicine and the paternalistic and death-denial attitude of its practitioners. One retired urologist laments that nowadays “[d]ying naturally is very difficult; there’s almost always a medical intervention at the end of life, because of the patronizing attitudes of the medical profession, they just want to keep on treating. The medical profession has been slow to understand the limits of medicine" (interview, Syme). Another physician says that in his opinion, "physicians, as a group, do not sufficiently recognize that death is the inevitable end for all of us. I sometimes think physicians tend to ignore this fact to an even greater extent than members of the general public" (affidavit, Welch). Conversely, proponents argue that those physicians who support PAD are very much cognizant of their own limitations and humble in the face of death: "But physician-assisted dying? Here we're talking about people who have a terminal illness who are dying, and the *physician is being humane and is accepting the reality that we can't fix you*" (emphases added, interviewee 26).

Proponents therefore see medicine as increasingly colonizing ever more parts of the end of life, to the detriment of dying persons. Indeed, with regards to end-of-life suffering, they lay a great deal of the blame at the feet of mainstream curative medicine. Proponents link suffering to the iatrogenic effects of life-prolonging interventions. They argue that these medical interventions are carried out within an enabling cultural context where life prolongation is a moral imperative and physicians are paternalistic and death-denying, thus further contributing to suffering. Curative medicine, then, is perceived by proponents to be complicit in the production of end-of-life suffering. We suggest that blaming, in this context, is both a moral and political act on the part of the proponents: it identifies a cause while at the same time obligates a particular group of actors (i.e., physicians) to redress the wrong.

The Limits of Palliative Care

In *Carter*, the proponents actively draw limits on what palliative care could accomplish in terms of relieving suffering. In particular, they argue that not all pain and symptoms could be alleviated with palliative care. We note first that the majority of proponents are unequivocal in their support for increasing the access and availability of palliative care. They diverge from opponents, however, in the latter's position that palliative care can address "the majority, if not all symptoms that may lead a person to consider ending their life" (factum, the Catholic Health Alliance of Canada).

Susan Bracken's affidavit describes her husband's experience dying from metastatic lung cancer in a palliative care ward. In our interview with her, she explains that the clinicians treating her husband "have almost all of the means for alleviating suffering. But there are some that they cannot, I know this is true for a fact because my husband's pain was terrible, and they were giving him morphine by pump and everything that he wanted, but he still was in terrible pain and moaning, and they could not stop the pain" (interview). Many of the physician-witnesses corroborate such experience in claiming in their affidavits or during interviews to have seen first-hand in the clinic the failure of palliative care in alleviating patients' pain and symptoms.

Opponents argue that in cases where patient's pain and symptoms are intractable, there is always the option of sedation. While sedation can be intermittent and of short duration, the type that is subject to contestation in *Carter* is what our participants call palliative or terminal sedation, which is the elimination of patient's consciousness until death, coupled with the removal of nutrition and hydration (which both parties recognize as a separate clinical decision). During the trial, Arvay references studies suggesting that sedated patients might still be suffering. In one cross-examination of a palliative care physician, he pushes for the witness to acknowledge this:

> Q: It's fair to say though, given this article and the one I've just read to you, you can't assure patients, you can't promise patients that with palliative sedation they will not suffer?
> A: I have to think about that for sure.
>
> (Trial transcript, McGregor.)

This excerpt comes at the end of a long exchange in which Arvay tries to press the point that in some cases, palliative sedation may merely be *masking* suffering. That is to say, while the intervention might be efficacious in reducing or eliminating observable signs of patient's consciousness, patients might in fact still be suffering intolerably until death.

Our participants argue that despite palliative care's efforts at holistic intervention (recall Saunders' notion of *total pain*), there are non-physical forms of suffering that lie outside of its ambit. Different participants use different terms to describe this suffering but the term 'existential' is commonly referenced. For Dying with Dignity, a right-to-die advocacy organization, existential suffering results "from profoundly diminished quality of life and a subjective experience of loss of dignity" (affidavit). Moreover, participants assert that such existential suffering is felt most acutely by patients with non-cancer diseases. We think it significant that out of the 18 lay affidavits describing witnesses' or their loved ones' illness experience submitted by the claimants, only two concern cancer. The rest describes experiences with various neurodegenerative diseases, such as Motor Neurone disease or ALS. Elayne Shapray, a woman with Multiple Sclerosis (MS), writes:

> The suffering I and others with progressive, degenerative illnesses such as MS endure, is both psychological and social, involving a loss of autonomy, independence, privacy and ability to do the things that give joy to one's life. These losses cannot be meaningfully addressed by any form of palliative care.
>
> (Affidavit, Shapray.)

In arguing that there are certain losses that cannot be addressed by palliative care, Shapray thus construes palliative care as irrelevant and unhelpful to her situation. Proponents use existential suffering as a discursive sign to denote a space of lived experience that lies outside of the reach of palliative care.

To be sure, there are those on the opposing side who acknowledge that palliative care "is not a panacea when it comes to eliminating all suffering. And it would be hubris to think that anything could eliminate suffering in every instance" (interview, Chochinov). But for the opponents, the limits of palliative care constitute a moral Rubicon that should never be crossed. As one of the interveners on the opposing side says, "I think if…you've done everything you can offer to a patient, and the patient doesn't want it [sedation], what you say is we've reached the limits of what medicine can do. But that's [PAD] not within the limits of what medicine can do. That's outside of medicine" (interview, Physicians' Alliance against Euthanasia). For opponents, then, the limits of palliative care themselves mark the very limits of medicine at the end of life.

The Production of Suffering in Palliative Care

Proponents go so far as to claim that palliative care interventions could exacerbate or prolong suffering. This is striking because this is the same charge that proponents levy on curative medicine and strikes a blow at the very heart of palliative care's professed mission of relieving suffering and counteracting the harmful effects of curative medicine (McNamara & Rosenwax, 2007; WHO, 2016).

The following exchange between Arvay and a palliative care physician testifying for the government is illustrative of the proponents' strategy. Under a framework of inquiry about typical palliative care interventions for an ALS patient, Arvay begins by asking the witness to confirm that “the physician will be able to explain to the ALS patient that at some point they will suffer pain for which they will require medication for relief, right?” The witness confirms that the majority of ALS patients will experience musculoskeletal pain and that although the first line of treatment would be acetaminophen, not opioids, if pain persists and not amenable to non-opioid drugs, then “ALS patients will come into an opioid or a narcotic-type medication at some point.” Arvay then asks a leading question: “And the family physician would be qualified to explain generally the side effects and 10 contraindications of some of these -- some of the medications?” After the witness responds affirmatively, Arvay points out that one of the common side effects of narcotics is constipation and counteracting constipation requires laxatives, which could cause diarrhea. The witness affirms that the use of laxatives is sometimes required. Arvay then moves to another symptom of ALS, incontinence, and employs a similar line of questioning: incontinence is addressed by the use of catheters, which could cause bladder infections. Arvay ends by asking if the physician “will be able to tell this patient…as he or she comes to the last few months of life they are going to be dependent on others for all of their care?” The witness, again, concedes that there will come a time during the illness trajectory when patients will become paralyzed (trial transcript, Downing).

Here, we see Arvay adroitly guiding the witness through a litany of problematic side effects produced by the very interventions meant to palliate the patient’s original symptoms (musculoskeletal pain and incontinence). The overall discursive effect is a manifold exacerbation of suffering, similar to Laforest’s lament on the mainstream medical interventions needed to prolong life. We are conscious of the risk of misinterpreting expressions of bodily dysfunctions – or disability for that matter – as suffering. It is clear, however, that proponents see the embodied changes brought about by illnesses (and their symptoms) along with the iatrogenic effects of medications or technology as profoundly abject. As the British Columbia Civil Liberties Association, one of the claimants, tells us, "an individual who had always taken great pride in being independent and adventurous and self-contained might find it deeply painful to have his wife feed him with a spoon…that's what this lawsuit is about" (interview).

Palliative sedation is further seen by proponents as potentially causing suffering for those standing vigil. Gloria Taylor writes in her affidavit of what she believes could happen were she to be sedated until death: "I believe terminal sedation would horrify and traumatize my 11 year-old granddaughter…her mind would be filled with visions of my body wasting away while I was 'alive'…I believe that would be cruel to my granddaughter" (affidavit). One physician says that it's "absurd" that "we don't allow ourselves as physicians to give you enough to let you die, but we can put you in a coma and keep you alive that way, that's a completely undignified way to end your life, and it just prolongs suffering for the family, to see you in a coma for days to weeks" (interviewee 26).

This derogation of palliative care is central to the claimants' argument that whether "the [patient's] condition is without remedy is to be assessed by reference to treatment options *acceptable* to the patient" (italics added, factum), and not by reference to whether or not treatment options exist *per se*. Demonstrating that the interventions of palliative care are unacceptable to some patients disabuses the notion that proponents are motivated by a blinkered desire for PAD. One of the government's witnesses, for example, believes that "the vast majority of [patients who want PAD] don't know and can't appreciate the full significance of the options they would have if they truly had…really good palliative care" (interviewee 1). Claiming that "really good palliative care" could have pernicious effects turns proponents' insistence for PAD into a seemingly rational, legitimate and necessary EOLC option.

The Significance of Physician-Assisted Dying

While there is disagreement among the proponents as to the scope of physicians' involvement in assisted dying, all agree on the necessity for the practice to be placed within a medical framework. The retired urologist we quoted earlier says that he is "opposed to approaches… to simply make information and medication available to people outside of a medical framework… This should not be something which the responsibility should be passed off, which some people have suggested to thanatologists or lay people who would carry out this work" (interview, Syme). During the trial, this emphasis on the role of medicine by proponents is brought into sharp relief by the Crown Counsel. Recall that the proponents' equality argument states that persons with disability are disadvantaged with regards to access to suicide. At the SCC hearing, the Crown Counsel remarks that it is "not that some people have a range of options and other people have none…there are options for ending life open to everyone, even the most severely disabled." She then presents refusal of nutrition and hydration as one example of those options. The Counsel argues that what the proponents actually want "is not access to assistance for the *usual means of suicide*, what they want is…access to a medicalized suicide" (emphases added, trial transcript).

We see the opposing side as narrowly interpreting the proponents' insistence for the medicalization of assisted dying in terms of the legal provision of lethal medication. In other words, opponents often reduce the significance of PAD to its final act only, the hastening of death. For example, Euthanasia Prevention Coalition, one of the interveners supporting the government's position, sees the question of euthanasia as one of "how are we going to get you out of this world as quick as possible" (interview). This reduction of PAD to its final act is concordant with another opponent's view of the practice as emblematic of "living in a quick-fix society" (interviewee 30).

Proponents do not disavow that placing PAD in a medical framework means that patients can gain access to the legal authority and technical competency of physicians in administering or providing (lethal) medication, thus guaranteeing a death that is quick and free from complications. However, we observe a repeated emphasis by the proponents on the interactive process, rather than the final act, mandated by a medicolegal regime of PAD and the ways in which that process can transform suffering at the end of life.

Proponents argue that placing the practice within a medical framework places the twinned moral obligations of medicine – maintaining life and relieving suffering – into conflict. On the one hand, this moral conflict functions as an important safeguard. As one public health researcher says, "I think that's sort of the point of [the involvement of] medicine is that medicine engages the skeptics who aren't really in favour of making this too easy" (interviewee 14). One the other hand, this moral conflict has the potential for improving patient-physician relationship. Proponents argue that when considering patients' requests for PAD, physicians would need to expend emotional labour to overcome the ingrained ethical obligation to maintain life and identify fully instead with patient's suffering. As one Dutch physician testifying for the claimants says, physicians "will have to bond with the patient in order to find out what the suffering of the patient really entails…What I meant by that is that still if you talk unbearable suffering and doctor and patient join in the decision that there really is unbearable suffering, there has to be an identification of the physician with what the patient goes through" (trial transcript). Thus, for physicians, placing PAD within a medical framework is generative of emotional labor that could reshape patient-physician relationship in important ways. Furthermore, proponents stress the significance of the regime for patients *even if the lethal medication is never used or obtained by the patient.* They argue that a medicolegal regime of PAD essentially functions as a crucial network of support for patients. As one lay witness with ALS writes, "[w]hat having the right to physician- assisted dying would do, more than anything, is lift the isolation and burden I feel as a dying person" (affidavit, Petrie).

DISCUSSION

Much of the research on the right-to-die movement focuses on the autonomy argument of the proponents, which is understandable given that their legal arguments make explicit appeal to autonomy-based human rights, such as the right to liberty, that are "the dominant global social justice ideology, the set of tools available to social justice activists" (Merry, 2014, 288). This article asks instead how PAD proponents articulate suffering with the role of medicine at the end of life. McInerney (2006; 2007) has studied the movement's "construction of the contemporary dying as horrific, intolerable, and beyond the ameliorative powers of medicine and palliative care" (2006, 664). However, her study analyses the *media representation* of this construction rather than the construction that emanates directly from the proponents' discourse, as we do here.

Focusing on autonomy may obscure other important considerations and present an incomplete picture of PAD. Beauchamp (2006, 644), for example, has argued that "this history [of PAD], still in the making, is a history of expanding commitments to autonomy." We argue that the story of PAD is *also* about the 'paradoxical' use (Richards, 2015) of the framework of the medicalization of dying by the proponents of assisted death in the 21st century. In this article, we have used *Carter* as a 'critical case' to investigate how 'suffering' is mobilised by proponents as a discursive construct to achieve their political goals. We began by providing background information on the Carter case. We then discussed the medicalization of dying prior to presenting our results. In the rest of this section, we reflect critically on the data.

We found that proponents construct different relationships among suffering, mainstream curative medicine, palliative care, and assisted dying. In the case of mainstream curative medicine, proponents highlight the profession's complicity in producing end-of-life suffering through the use of life-prolonging interventions. In social movement studies, "diagnostic framing" refers to the process of defining a social problem and focusing blame or responsibility (Benford & Snow, 2000). Here, proponents fault the cultural context of medicine where life-prolongation is a moral imperative and physicians are paternalistic and death-denying. In the case of palliative care, proponents emphasize its limitations and, like mainstream medicine, its exacerbation of suffering at the end of life. In this way, proponents impose a limit to the therapeutic reach of palliative care that comes to be seen as legitimate and rational, rather than (merely) politically expedient.

It should come as no surprise that in the debate over legalization, proponents see the need to problematize the relationship between palliative care and suffering in EOLC; if palliative care is fully capable of alleviating suffering, there would be no need for PAD. Palliative care professionals have been one of the most vocal stakeholders in the debate and most of them have voiced public opposition to PAD. Further, as palliative care developed, it has been able to claim "measurable and striking successes” (Clark & Seymour, 1999, 906) in pain and symptoms management. Proponents claim that such successes need to be qualified. As our study participants argue, the ability of palliative care to relieve suffering has limits which they locate in the suffering of persons with non-cancer diseases. Indeed, the discursive space taken up by talk and text of neurodegenerative illnesses by the proponents – via their discussion of ‘existential suffering’ – is disproportionately larger than that of cancer considering that evidence from permissive jurisdictions shows cancer patients making up the majority of persons requesting and accessing PAD (Smets et al., 2010; Oregon Health Authority, 2015). Proponents also point out that even in palliative care’s traditional area of strength – cancer care – not all suffering could be mitigated. Proponents thus charge as illusory palliative care’s goal of addressing ‘total pain’. Proponents even go so far as to make the bold claim that palliative care interventions could cause suffering. These interventions range from the conventional use of opioids (as having “10 contraindications”) to the more controversial use of palliative sedation where proponents argue that palliative sedation could, in fact, cause additional suffering in those keeping vigil by the bedsides of dying persons.

Proponents’ discourse on palliative sedation merits greater attention because it has implications for palliative care’s claim that it provides “impeccable assessment and treatment of pain and other symptoms” to people facing life-limiting illnesses (WHO, 2016). Proponents argue that palliative sedation merely masks, rather than alleviates, suffering. Citing Morris (1997), Clark and Seymour (1999) note that palliation used to be a pejorative term in the medical lexicon due to the double meaning of palliation: one the one hand, to cloak, and on the other hand, to shield. When used in the first sense, palliation was seen to be a failing of medicine for it only disguised or covered up symptoms leaving the underlying diseases untouched. In arguing that palliative sedation only covers up bodily expressions of suffering while leaving the suffering itself untouched, we see proponents resurrecting and inscribing the pejorative sense of palliation to palliative sedation specifically and palliative care in general.

One widespread assumption in the debate over PAD is that physician-assisted suicide and euthanasia constitute the “ultimate brakes on the unrestrained use of medical technology at the end of life” (Salem, 1999, 30). In other words, PAD practices “are the instruments that promote the ‘demedicalization’ of death” (ibid.). Our analysis shows how such an assumption may come to be; proponents’ articulation of suffering with mainstream medicine and palliative care seemingly point to their absolute rejection. However, as Salem (1999) has trenchantly argued, it would be a mistake to adopt this assumption uncritically.

It needs to be made explicit that the Criminal Code makes no specific mention of the construct of *physician*-assisted dying. The provisions challenged by the claimants *collectively have the practical effect* of prohibiting PAD. The claimants did not seek a wholesale invalidation of those provisions. Rather, they sought a declaration of invalidity for those provisions *only in the context of PAD*. We mention this to highlight the fact that from the outset the claimants had no intention of advocating for a system in which assisted dying would be placed outside of a medical framework. As the Crown Counsel made cogently clear in her address to the SCC Justices, what the proponents wanted was *medicalized* assisted dying. The proponents could have pushed for a Swiss-type change in law. In Switzerland, the act of assisting in another person’s suicide is not illegal so long as it is done without selfish motives (Hurst & Mauron, 2003). The Swiss regime does not require the participation of physicians and consequently allows for non-physicians (and non-healthcare professionals in general) to play an important role. In *Carter*, the proponents stress instead the absolute necessity of the participation of physicians in any subsequent regime. In fact, looking more broadly beyond Canada, with the exception of Switzerland, in all places where legal regimes have been instituted, the social and cultural legitimacy of assisted dying has required it to be located within a medical framework (Timmermans, 2005). As Ost (2010, 7) aptly observes:

> Significantly, legal, ethical and social discourses surrounding assisted dying and laws that have permitted assisted dying have tended to focus on the assistance of doctors, the provision of medicine to cause death and medical grounds for requesting death, that is pain and suffering derived from medical conditions. As such, medicine has provided the main frame of references, a vital component of the phenomenon of assisted death.

This, then, suggests to us that the medicalization of dying, far from being seen as a constraining framework for proponents, is used by them for constructive ends. This conclusion is supported by our data whereby the proponents argue that the significance of a PAD regime lies beyond the legal provision of lethal medication. To be sure, their insistence on medical control is also meant to temper the fear of harm to the vulnerable. Nevertheless, they emphasize what they see to be the transformative power of physicians' involvement in PAD. Proponents argue that in order to satisfy the due care criteria of a permissive regime, physicians need to form an empathic bond with patients. From the patient's perspective, such involvement of physicians – and healthcare professionals more broadly – *could have an alleviating effect on suffering* by reconstituting and strengthening the dying person's social network, even if the process does not culminate in the provision or administration of lethal medication. Indeed, Norwood's (2007; 2009) ethnography of euthanasia in the Netherlands shows how the practice exists mainly in the form of therapeutic talk and that such talk has the function of reaffirming social bonds by encouraging open dialogue between patients, families, and healthcare professionals. In this way, the right-to-die and palliative care movements actually come to share a “medical-revivalist discourse” in which “death (again) becomes something that should be talked about without embarrassment” (Van Brussel, 2014, 18).

Medicalization is a widespread phenomenon that has transformed many aspects of social life (Conrad, 2013), including dying. Reading through the medicalization of dying literature, one cannot help but be struck by the overwhelming negative tone by authors on the medicalized forms of contemporary dying (Glaser & Strauss, 1966; Glaser & Strauss, 1980; Halper, 1979; Illich, 1976; IOM, 2014; McNamara & Rosenwax, 2007; Sudnow, 1967; Timmermans, 2010). In essence, critics argue that the involvement of medicine at the end of life has served only to increase, rather than attenuate, suffering. In this article, we’ve shown how one group of actors not only reproduces but expands this line of critique to include palliative care. However, it would be a mistake to interpret proponents’ rejection of the status quo as a rejection of medicine. That is, PAD proponents are not trying to demedicalize the dying process. In fact we have shown how the proponents use the medicalization framework for emancipatory ends. While such productive use of the medicalization framework by social movement actors has been observed elsewhere (Conrad, 2013; Torres, 2014), the significance of our findings and analysis must be considered in light of the fact that the right-to-die movement emerged historically as a counter-response to medicalization. Discussing the right-to-die movement and palliative care, McInerney observes that these were two voices “in the growing critique of medicine’s omniscience in relation to death, and of the situation for many individuals at life’s end” (2000, 141). In this article we have shown how such critique by the proponents of PAD has not resulted in the demedicalization of dying in the 21st century. We argue that their articulation of suffering with the role and place of medicine at the end of life must instead be understood as a discourse through which one configuration of EOLC comes to be rejected and another accepted, a discourse that does not at all challenge the larger framework of the medicalization within which contemporary dying is experienced.

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CHAPTER 4

BORDER DISPUTES: PHYSICIAN-ASSISTED DYING AND THE BOUNDARIES OF END-OF-LIFE CARE PRACTICES

ABSTRACT

In the contemporary debate over the legalization of physician-assisted dying (PAD), the practice of PAD is often compared with and contrasted to the practices of withholding and withdrawal of life-sustaining treatment, palliative sedation, and opioid use. While there has been much discussion in bioethics and legal scholarship on the ethical distinction between these practices, less attention has been paid to how the disputes between the opponents and proponents of legalization on this matter actually unfold in a concrete instance of the debate. The landmark case of *Carter v. Canada*, which resulted in the decriminalization of PAD in Canada in 2015, provided us with an empirical opportunity to study these disputes. Through an analysis of the legal documents generated by the case and in-depth interviews with its key participants, we found that opponents rigorously policed the boundaries at three different 'sites': around the issues of physician's intent to kill, whether the other end-of-life care (EOLC) practices can cause death, and the 'naturalness' of those practices. Proponents, on the other hand, rejected the ethical distinction by emphasizing the active role of the physician in the other EOLC practices, making visible perceived inequality in EOLC for patients, and pointing out the professional capacity for EOLC decision-making that already existed in Canadian medicine. We conclude by discussing aspects of the social context that we believe shaped the proponents' and opponents' discourse.

KEYWORDS: Physician-assisted dying, withholding and withdrawal of life-sustaining treatment, palliative sedation, the use of opioids, *Carter v. Canada*, end-of-life care, border dispute.

INTRODUCTION

In the contemporary debate over the legalization of physician-assisted dying (PAD), its practice (which includes euthanasia and physician-assisted suicide) is often compared and contrasted with the practices of withholding and withdrawal of life-sustaining treatment, palliative sedation, and opioid use. The orthodox positions in bioethics and law maintain that there is an ethical distinction between PAD and those other EOLC practices. Therefore, the boundaries between the practices can be discerned. Most of the opponents of legalization accept the validity of this position while most of the proponents do not (Devettere, 1989). While there has been much discussion in bioethics and legal scholarship on the ethical distinction between PAD and the other EOLC practices, less attention has been paid to how the disputes between the opponents and proponents on this matter unfold in a concrete and legally-binding instance of the debate. The case of *Carter v. Canada* afforded us with an empirical opportunity to observe and analyze these disputes. *Carter* was a landmark litigation that resulted in a Supreme Court of Canada (SCC) decision overturning the Criminal Code prohibitions on PAD. In response, in June 2016 the Parliament of Canada passed a legislation legalizing PAD, making Canada only the 13th jurisdiction in the world to have decriminalized or legalized the practice.

Our aim in this article is to document and analyze the ways in which stakeholders demarcate or collapse the boundaries between PAD and the other EOLC practices. We proceed by first providing definitions of the practices, after which we present background information concerning *Carter*. We then provide details of the ethical and legal landscape of the other EOLC practices before describing the methodology of our study. In the results, we argue that opponents rigorously policed the boundaries at three different ‘sites’: around the issues of physician’s intent to kill, whether the other EOLC practices can cause death, and the ‘naturalness’ of the other EOLC practices. Proponents, on the other hand, rejected the ethical distinction by emphasizing the active role of the physician in the other practices, making visible perceived inequality in EOLC for patients depending on which practice their condition allows them to access, and pointing out the professional capacity for EOLC decision-making that already existed in Canadian medicine. We conclude by discussing various aspects of the social context that we believe have shaped the opponents’ and proponents’ discourse on the boundaries between PAD and the other EOLC practices. This article contributes to studies in sociology of bioethics and empirical bioethics, analyzing “how ethics gets done on the ground, how…terms pick up specific meanings within institutional contexts, and how the same actions can be interpreted differently depending upon social location” (De Vries et al., 2006, 677).

ON TERMINOLOGY AND THE POLITICS OF NAMING

We provide readers here with definitions of the practices generally accepted by bioethicists, end-of-life care researchers, and policy makers that are the subject of this article and introduce a couple of key concepts mobilized by the participants in *Carter* (see Table 2). We are cognizant that definitional processes – how different actors offer competing and overlapping definitions of a phenomenon – are central to the construction of social problems (Gusfield, 1981, 1996; Spector & Kitsuse, 1977). Thus, we make no claims as to the ‘truth’ of these definitions (i.e., we are agnostic on the issue of whether these descriptions accurately ‘capture’ or represent the actual practices).

Terms	Definitions
Euthanasia	The administration of drugs with the explicit intention of ending the life of the patient at his/her request
Assisted suicide	The act of killing oneself intentionally with the assistance of another who provides the means, the knowledge, or both
Physician-assisted suicide (PAS)	Assisted suicide in which the assistance is provided by a physician
Physician-assisted dying (PAD)	An umbrella term used by the *Carter* claimants to refer to both PAS and euthanasia
Withholding of life-sustaining treatment	The act of not starting a life-sustaining treatment, which includes artificial hydration and nutrition
Withdrawal of life-sustaining treatment	The act of stopping life-sustaining treatment, which includes artificial hydration and nutrition
Passive euthanasia	An umbrella term traditionally used to refer to withholding and withdrawal of life-sustaining treatment
Palliative sedation	The therapeutic reduction or elimination of consciousness, either intermittently or continuously, when there is no other way to relieve the intractable suffering of patient
Opioids use	The use of opioids for the treatment of pain, dyspnea, and cough
Sources: Van der Maas et al., 1991; Roy and Rapin, 1994; The Special Senate Committee on Euthanasia and Assisted Suicide, 1994; Sykes and Thorn, 2003; Dieterle, 2007; Claessens et al., 2007	

Table 2: Terms and definitions of end-of-life care practices

Some elaborations on the definitions provided in Table 2 are in order. Sedation can be intermittent or it can be continuous until patient's death; it can also be light or deep. In this article, when we refer to palliative sedation, we are referring exclusively to the practice of continuously and deeply sedating patients until death (also referred to as 'terminal sedation'). Graeff and Dean (2007) recommend that the decision to withhold or withdraw nutrition should be made separately from the decision to initiate sedation; they also advise that sedation be administered only to patients whose deaths are expected within hours or days. The use of opioids can cause respiratory depression; however, such serious side effect is rare for patients whose dose has been carefully titrated against their pain (Alpers, 1998). Physicians have, however, admitted to using opioids to hasten their patients' deaths. In 1998, for example, the

Journal of American Medical Association published a controversial article, “It’s over Debbie,” in which an anonymous physician described injecting an ovarian cancer patient with morphine sulfate to hasten her death (Anonymous, 1988).

The term ‘physician-assisted dying’ is used by the claimants in *Carter* in their official submissions to the court to bring both euthanasia and physician-assisted suicide (PAS) under one rubric. The term ‘passive euthanasia’ derives its meaning from the omission/commission distinction where the adjective ‘passive’ is used to describe the physician’s act as one of omission, rather than commission. In other words, it is argued that in withholding and withdrawal of life-sustaining treatment, the physician is not actively ending the life of the patient (Blank, 2011). Although the term, passive euthanasia, is increasingly falling out of favor (Garrard & Wilkinson, 2005), the *Carter* claimants employed it as part of their ‘labeling politics’ (Zerubavel, 1993). The *Carter* claimants called withholding and withdrawal of life-sustaining treatment, palliative sedation, and opioids use ‘passive euthanasia.’ We have written elsewhere about how stakeholders in the case understood the naming of the practices to be consequential; that is, stakeholders viewed it as an intentional act designed to mobilize certain emotions and advance a particular version of the ‘reality’ of PAD (Karsoho et al., 2016). Calling the other end-of-life care (EOLC) practices ‘passive euthanasia’ was a deliberate attempt to signal that the practices were, in spite of the qualifier ‘passive,’ still euthanasia.

BACKGROUND: *CARTER V. CANADA*

In 1992, Sue Rodriguez, a British Columbian woman with Amyotrophic Lateral Sclerosis (ALS), challenged the constitutionality of the Criminal Code prohibition on physician-assisted suicide, arguing that it contravened her rights guaranteed under *the Canadian Charter of Rights* *and Freedom*. After losing in the provincial courts, she appealed to the SCC. On September 30, 1993, the SCC ruled against her in a 5-4 decision, finding that although her rights had indeed been violated, the government had successfully demonstrated that nothing short of a blanket prohibition could protect the vulnerable. *Rodriguez v. British Columbia* [Rodriguez v. British Columbia (Attorney General), 3 S.C.R. 519, (Can.)] had therefore set the precedent with regards to PAD when the *Carter* case began.

Carter formally began on April 26, 2011 when the claimants filed notice of civil claim at the Supreme Court of British Columbia (the province's court of first instance). The original claimants consisted of Lee Carter and her husband Hollis Johnson, both of whom had accompanied Carter's mother to die at a Swiss assisted suicide clinic the year before, Dr. William Shoichet, a family physician, and the British Columbia Civil Liberties Association (BCCLA), a civil rights advocacy organization. On August 15, Gloria Taylor, a woman with ALS, joined the litigation as the fifth plaintiff. The case also saw the participation of 97 expert and lay witnesses and 26 interveners. Unlike in *Rodriguez*, the claimants challenged the constitutionality of the Criminal Code prohibitions on both PAS and euthanasia (under the rubric of 'PAD') and named the federal government as defendant. On June 15, 2016, the trial judge in the case, Smith J., found for the claimants, a decision that was subsequently reversed by the Court of Appeal. The majority opinion in the appeal stated that the trial judge was ultimately bound by *Rodriguez.* The SCC granted the claimants leave to appeal and they heard oral arguments on October 15, 2014. On February 6, 2015, the Justices released its decision in which they agreed with the claimants and struck down the Criminal Code prohibitions on PAD. The decision was unanimous and signed by 'The Court.' Bzdera (1993) suggests that such 'single anonymous opinion' by the Court is meant to add greater authority to the decision because it is attributed to the institution of the Court rather than any individual Justices.

Of particular relevance to our inquiry here is Smith J.'s finding that there was no ethical distinction between PAD and other end-of-life care practices that might hasten death. While this finding was not a direct response to the legal question that was the crux of the case (i.e., whether or not the prohibitions on PAD were constitutional), it formed part of the trial judge's reasoning and contributed to her final decision. The SCC did not contradict Smith J. on this matter and subsequently observed in its ruling that:

> After considering the evidence of physicians and ethicists, she [i.e., Smith J.] found that the 'preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death' (para. 335). [Carter V. Canada (Attorney General) 2015 SCC 5, para. 23]

This was not the first time that a court had found that there was no ethical distinction between PAD and other EOLC practices. In *Washington v. Glucksberg* [521 U.S. 702 (1997)], the U.S. Court of Appeals for the 9th Circuit declared there to be no ethical distinction between forgoing lifesaving treatment and PAS. The U.S. Court of Appeals for the 2nd Circuit, in *Vacco v. Quill* [521 U.S. 793 (1997)], came to a similar conclusion. The U.S. Supreme Court, however, would later reject the lower courts' finding and defend the distinction without explicating or justifying its position (Sulmasy, 1998).

THE ETHICS AND LEGALITY OF END-OF-LIFE CARE PRACTICES

Discursive activities in the bioethics and legal arena show the ethics and legal status of PAD to be bound up with the ethics and legality of the other EOLC practices. That is to say, when commentators attempted to define the ethical and legal boundaries of withholding and withdrawal of life-sustaining treatment, palliative sedation, and the use of opioids, they invariably needed to define them in contradistinction to PAD. For those who consider PAD to be a moral badness and its legal prohibition to be justified, attempts must be made to construct the other EOLC practices to be different from PAD and thus placing them on the 'right' side of the ethical line.

The position that there is an ethical distinction between withholding and withdrawal of life-sustaining treatment and PAD has been described as the "traditional view" in medical ethics (Sulmasy, 1998). Callahan's (1989) position is perhaps the most representative of the traditional view in that it upholds the omission/commission distinction and argues for the primacy of the disease as the causative agent in the patient's death. For the proponents of PAD, James Rachels' (1975) seminal paper on 'active and passive euthanasia' remains a touchstone; he argues that in withholding and withdrawal, the physician is not entirely passive: he lets the patient die. Thus, the omission/commission distinction does not hold: omission can have causal effects. "The bare difference between killing and letting die does not, in itself, make a moral difference," argues Rachels (1975, 219). He further argues that either the physician's EOLC decision is morally right or wrong and "the method used is not itself important" (Rachels, 1975, 209).

Canadian courts have, until *Carter*, affirmed the ethical distinction between withholding and withdrawal on one hand and PAD on the other. The leading case on the permissibility of withholding and withdrawal is the 1992 case of *Nancy B. v. Hôtel-Dieu-de-Québec* which concerned a 25 year-old patient with Guillain-Barre syndrome paralyzed below the neck and attached to a mechanical ventilator (Nicol & Tiedemann, 2016). She had twice asked for the ventilator to be removed, requests which were denied by her physician and the hospital for fear of criminal liability. Nancy B. subsequently sued the hospital and the judge convened the court in her hospital room. Dufour J. agreed with Nancy B.'s argument that as a medically competent patient, medical treatment could not be maintained without her informed consent. Five weeks after the ruling, Nancy B. was induced into a coma and her ventilator removed. She subsequently died. The significance of the decision was twofold: first was the legal finding by Dufour J. that death from withdrawal constituted a 'natural death': "I would however add that homicide and suicide are not natural deaths, whereas in the present case, if the plaintiff's death takes place after the respiratory support treatment is stopped at her request, it would be the result of nature taking its course" [B(N) v. Hôtel Dieu de Qué (1992) A.Q. no 1]. Second, in finding that refusal of treatment leading to death was legally permissible, Dufour J.'s decision implicitly affirmed the distinction between withholding and withdrawal on the one hand and the legally prohibited act of PAD on the other. Dufour J.'s decision has been cited and approved by other Canadian courts, including the SCC in *Rodriguez* (Lemmens & Dickens, 2001).

Those who defend the ethical distinction between opioid use and PAD have often relied on the foresight/intention distinction derived from the doctrine of double effect to distinguish from PAD opioid use in dosages that may potentially hasten death. The doctrine of double effect refers to the ethical rule that states that "an action with both good and bad effects may nevertheless be morally justified, provided that only the good effect is intended and the bad effect merely foreseen, and provided that the action itself is morally permissible, that the bad results are not means to the good end, and that the good achieved thereby is great enough to outweigh the bad" (Nuccetelli & Seay, 2000, 19). In other words, potentially life-shortening opioids use is ethically acceptable so long as death is merely foreseen rather than intended by the physician and that the ultimate aim is the relief of patient's suffering. The issue of ethicality and legality of opioid use at the end of life has been considered very infrequently in common law jurisdictions. Nonetheless, the few court decisions in the U.S. and in Britain that have considered the issue "provide support for a legal distinction between foresight and intention as a basis for upholding the lawfulness of aggressive palliative care" (Magnusson, 2006, 561). In Canada, *Rodriguez*, Sopinka J., writing for the majority, states:

> The fact that doctors may deliver palliative care to terminally ill patients without fear of sanction, it is argued, attenuates to an even greater degree any legitimate distinction which can be drawn between assisted suicide and what are currently acceptable forms of medical treatment. The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes an active contribution by any standard. However, the distinction drawn here is based upon intention – in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause death [Rodriguez v. British Columbia (Attorney General), 3 S.C.R. 519, (Can.), p. 607].

Decisions such as that of Sopinka J.'s has led Magnusson to conclude that the doctrine of double effect has been used by the courts (and ethicists) to excuse physicians from criminal liability.

The courts in *Rodriguez* did not consider the issue of palliative sedation. Indeed, no Canadian courts have issued judgment with regard to the legality of the practice, leading some commentators to describe its legal status in Canada at the time of *Carter* as "very unclear and potentially very controversial" (Schüklenk et al., 2011, 34). In contrast, the U.S. Supreme Court has considered the issue in *Vacco* [Vacco v. Quill, 521 U.S. 793 (1997)] and *Glucksberg* [Washington v. Glucksberg, 521 U.S. 702 (1997)] and decreed palliative sedation to be ethically acceptable and legal on the basis of the doctrine of double effect. For many bioethicists, however, the ethics of palliative sedation is far from settled. As Bruce and Boston (2011, 2735) claim, “Palliative sedation remains an uneasy practice. As it deliberately induces a deep sleep during which some patients do not receive food or water and from which many patients do not wake, palliative sedation evokes ethical questions and has been described as slow euthanasia.”

METHODOLOGY

This article draws from our original, empirical investigation of *Carter v. Canada*. The study itself is part of a larger research project analyzing the public controversies over medicalized dying in Canada. Prior to data collection, the study received research ethics approval from McGill University. We collected and analyzed all of the legal documents generated by the case: the affidavits (evidence of the expert and lay witnesses), factums (position statements submitted by the claimants, government, and interveners), and trial transcripts, amounting to over 4,000 pages of text. We obtained all of the legal artefacts that originated from the provincial courts directly from the Crown Counsel. The legal documents originating at the SCC level were obtained directly from the court.

For the interviews, we approached the claimants, interveners, and select lay and expert witnesses. For the witnesses, we selected only those with the most ‘impact’ in the case. Venturini (2010, 262) observes that “actors are not born equal in controversies;” the impacts of actors’ interventions in a controversy may vary considerably. We operationalized impact according to two criteria. First, we defined as impactful those interventions by witnesses that resulted in their opinions being cited by the judges. Second, we looked to see which witnesses were selected by the counsels (both the claimants’ and the government’s) for cross-examination. Our recruitment process resulted in interviews with 42 participants of the case. All interviews were audio recorded and transcribed. Informed consent, either written or verbal, was obtained from each participant. Those we name in this article have given us permission to identify them publicly. Data collection spanned 21 months from July 2013 to March 2015.

This article focuses on one aspect of the data: the participants' discourse on PAD and other EOLC practices. Following Potter (1996), we understand discourse to be talk and text *in action*. In other words, discourse is a *process* by which actors use language to build their versions of reality, in order to achieve some pre-determined goals. This is a theoretical understanding of discourse that is informed by insights from the sociology of knowledge. We therefore do not reify discourse as a free-floating ontological entity that can be studied apart from the actors producing it and its local context of production. As Keller (2006, 6) argues, "In the empirical world, we can't collect anything but disparate elements of utterances, occurring at different instances in time and social as well as geographical space. Discourse so far is nothing but a theoretical device for ordering and analysing data, a necessary hypothetical assumption to start research." Our methodological framework understands discourse to be something that people *do* consciously and deliberately rather than something that happens to them.

After uploading all data to Atlas.ti^{TM}, a computer-assisted qualitative data analysis software, we selected for in-depth analysis all 'utterances' by stakeholders involving PAD and other EOLC practices. Using constant comparative analysis techniques (Glaser & Strauss, 2009), the analytical process sought to discern themes or patterns across the data; it also proceeded iteratively with consultation with the broader legal, bioethics, and sociological literature. In particular, we used insights from scholars who have theorized about boundaries as it became clear early in the analytical process that we were observing an empirical example of what Zerubavel (1993, 67-69) calls ‘border dispute’: “a battle over the location of some critical line in actual space…such [border disputes] are basically about whether what may look like several separate entities are indeed just variants of a single entity.” Such social entities as human practices, however, must be understood as products of boundaries (Abbott, 1995). This means that boundaries are not discerned by actors because they correspond to some pre-existing contours of entities; rather, entities are formed through the drawing of boundaries. As Abbott (1995, 860) argues, “Boundaries come first, then entities.” According to Abbott, actors link up ‘proto-boundaries,’ which are conceptual sites of difference, to form social entities. In analyzing the data, we thus asked ourselves what, for the opponents, constituted sites of difference between PAD and the other EOLC practices? How did they tie these sites together? How did the proponents respond to such demarcation activities by the opponents? Further, we saw the analysis of the border disputes between the opponents and proponents of PAD as an opportunity to learn something about either the stakeholders or aspects of the larger debate over PAD. In this regard, we followed Scully (2001, 194) in her approach to studying boundaries, an approach she calls ‘reverse ethics’:

> In this approach our concern would not initially be to find the right location for the boundary, but to notice where it has been placed by a defined group of people. Then, working from this empirically determined site, information about the external and internal constraints...that provide the boundary's context can be uncovered. Only glancing attention is paid to the site of the boundary itself. Instead, it is used as our basecamp for an exploration of the surrounding moral terrain to find out - as far as we can - what factors have caused that group of people to construct a moral issue in such a way that the place of transition between right and wrong occurs just there.

This ‘reverse ethics’ approach guided the inferences that we made in the discussion section, where we suggested aspects of social context that we believed shaped the ways stakeholders drew or collapsed the boundaries between PAD and the other EOLC practices.

RESULTS

In this section, we present the opponents’ discourse followed by the proponents’. By opponents, we mean the government as well as those participants whose text and talk it strategically enrolled to oppose the decriminalization and legalization of PAD. Proponents refer to those on the other side. We first describe the overall ‘tone’ of each discourse, followed by the themes that constitute that discourse.

Opponents’ Discourse: Policing the Boundaries

We discerned an overarching framework in the opponents’ discourse on the boundaries between PAD and other EOLC practices, a framework that we describe here as ‘policing the boundaries.’ Opponents’ discourse evinced disquiet around what they perceived to be widespread misconceptions among the public at large as well as the medical profession about EOLC that they felt conflated and confused the demarcations between the other practices and PAD. The executive director of Euthanasia Prevention Coalition (EPC), an intervener, told us that when he was making presentations to the public, “I make it very clear, euthanasia is not withdrawing treatment; euthanasia is not using large doses of pain-killing drugs” (interview). The Canadian Medical Association (CMA) intervened only at the SCC stage in 2014 and presented itself as neutral with regards to PAD. Prior to its entry in the case, however, it had an explicit policy published in 2007 opposing PAD, which the government submitted as evidence. This policy began with formal definitions (and opposition) of only three practices: aid in dying, euthanasia, and assistance in suicide. In 2014, the CMA began to revise its stance, and accordingly, its policy. The first changes made to its policy was the addition of formal definitions for, among others, palliative sedation, withholding and withdrawal of life sustaining treatment, and palliative care. When we asked why they felt there was a need for these definitions, the CMA representative told us that the organization wanted to “clarify things around things like withdrawal of care” and to “take back some of the language” from different parties (i.e., proponents) that were muddying the “professional and public understanding of the issue” (interviewee CMA). We thus saw the opponents proactively policing the boundaries of the other EOLC practices. Our analysis of the data shows such policing to occur at three different ‘sites of difference’: the absence or presence of physician’s intent to kill, whether the other EOLC practices actually caused death, and the ‘naturalness’ of the other EOLC practices.

Physician’s Intent to Kill

Intent to kill was the strongest theme that we observed in the opponents’ discourse distinguishing PAD from the other EOLC practices. Further, it was the *physician’s* intent, rather than the patient’s, that was morally significant for the proponents. In other words, even if a patient on life-sustaining support requested for the removal of the medical treatment with the intent to kill himself/herself, the physician could comply with the request under such reasons as medical futility or relief of suffering, but not with his/her own intent to kill. For the opponents, the boundaries between PAD and the other EOLC practices would disappear if there was physician’s intent to kill. As one bioethicist testifying for the government stated, he saw no “moral difference between the positive act of a doctor who administers lethal injection with the intent to kill a competent adult patient who requests the same and the decision of a doctor who agrees to withdraw a feeding tube from a [competent] patient…who asks for it with the intent to die and the doctor agrees to it with the intent to kill (trial transcript).”

The issue of physician’s intent to kill implicated an additional concern in *Carter*: whether or not it was legally distinguishable from the act of foreseeing death. Many of the witnesses and interveners opposing PAD argued, using the doctrine of double effect, that even if the physician foresaw that death was likely to occur in carrying out the other EOLC practices, the physician could still act without the intent to kill. The government, however, conceded during trial “that the Canadian criminal law does not recognize a distinction between intentionally killing a person and committing an act knowing that death may be a likely or foreseeable outcome” (factum). Many of the interveners believed that this concession was instrumental in the trial judge’s finding that there was no ethical distinction between PAD and the other EOLC practices.

Causing Death

The question of whether the other EOLC practices *actually caused death or shortened life was* an empirical (or rather, factual) question that received much attention during the trial. The opponents conveyed mixed message in responding to this question. Some hedged their answers by saying that the other EOLC practices did not *inevitably* cause death. As the EPC argued, “in euthanasia, you’re giving me a lethal injection now…and I’m going to die for sure” (interviewee EPC). The EPC representative says that if he were on a ventilator, “you can withdraw the ventilator from me and guess what, I might keep breathing!” He added that if he were to die, he would die from the underlying medical condition rather than from the withdrawal of ventilator. Speaking of palliative sedation, a palliative care physician stated that because the practice was typically administered to dying patients, “in many cases or in some case it’s difficult to know whether [the death] is from the dying or from the palliative sedation. But we know from studies that it doesn’t invariably shorten life” (trial transcript). Such hedging practices by the opponents expressed uncertainty as to the cause of death when the other EOLC practices were involved.

With regards to opioids for the opponents, it was not its use that inherently carried a significant possibility of hastened death, but rather its misuse by incompetent practitioners. As one palliative care physician wrote, “It is correct that if [morphine and similar drugs] are used inappropriately they do have side effects of depressing respiration” (affidavit, Finlay). There was, then, a right way to carry out the practices and one had to acquire specific training and knowledge in order to do so, in the opponents’ view. In fact, this lack of the right knowledge and training was seen by many to be behind the misconceptions surrounding the practices that they caused or hastened death. Another palliative care physician told us that “there are many professionals in practice today that have never undergone adequate training in palliative care (interviewee 30).” He added:

> I’ve always said that opiates is like a car, if you drive it safely, it’s safe, but if you drive it dangerously it can be dangerous, but not enough people are being trained on how to do it safely, and there’s still too many myths out there about it.

For this physician, knowing how to use opioids correctly was akin to being a part of a community of safe drivers: it required socialization into a specific way of thinking and doing end-of-life care. In drawing boundaries around the other EOLC practices, we thus saw the opponents as also drawing boundaries around a specific community of experts, separating those with a particular kind of knowledge and training (i.e., palliative care expertise) from those without.

The Naturalness of the Other End-of-Life Care Practices

In discussing PAD vis-à-vis the other EOLC practices, opponents rejected the appropriateness of the label 'end-of-life care' for PAD. Council of Canadians with Disabilities (CCD), a national disability rights group, was one of the interveners supporting the government's position. We spoke to a representative of the group and when we asked why she thought PAD had become a national, EOLC issue, she made it clear to us that she did not see PAD as an 'end-of-life' issue. The label EOLC, according to CCD, more properly described such practices as the withholding and withdrawal of life-sustaining treatment from a dying patient. She said:

> [W]hat we have chosen at CCD to do is to change that word [from end] to 'ending'[for PAD] because it's an active verb and ending of life. If the person is at end of life, are they at end of life because their body has naturally come to the point where it can no longer sustain itself, they've lived the life that they want to live, and they are at that point where, yes, you know, I am now requesting…that I receive no more treatment that would sustain that life. Or is it end of life because someone has decided that their life is no longer worth living? (Interview).

Similarly, a bioethicist who was an expert witness for the government questioned the title of our research project ("The Ethics of End-of-Life Care") at the start of our interview with him. He insisted that "this is not really about end of life. This is about ending life." End of life, he continued, is a stage "in which nothing can be done to cease the dissolution of the person" (interviewee Koch). In this context, therefore, the use of life-prolonging treatment merely interrupted a process that was already ongoing – "the dissolution of the person." Removing the intervention meant simply returning the body to the inevitable process of dying. The palliative care physician we quoted earlier said that palliative sedation, “by definition is for patients who are at the end of life.” And, according to him, “it does not mean that you stop, that one intentionally stops the hydration, but that people are really eating less and drinking less and stopping naturally at the end of life” (interviewee 30). Ending life, on the other hand, is “when, for one reason or another, people premeditatedly terminate a life which could be ongoing” (interviewee Koch).

Opponents’ rejection of PAD as an end-of-life care issue performed two functions. First, it naturalized (and normalized) the other EOLC practices. These were practices that opponents saw as properly belonging to the discursively constructed realm of ‘end of life’ because “their body has naturally come to the point of where it can no longer sustain itself.” By appealing to the natural, the opponents asserted the common sense nature of the other EOLC practices. In contrast, PAD was not a ‘natural’ practice concordant with the physiological processes of dying. Indeed, proponents saw PAD as an artificial (i.e., man-made) intervention into the life process (“people premeditatedly terminate a life that could be ongoing”).

Proponents’ Discourse: A Logical Progression

Proponent’s discourse revolved around what they perceived to be the hypocrisy of the law. For the proponents, there was no ethical distinction between PAD and the other EOLC practices. It was therefore illogical, in their view, for the law to prohibit PAD while permitting the other EOLC practices. The claimants submitted evidence to establish that the other EOLC practices – withholding and withdrawal of life-sustaining treatment, in particular – were commonplace in Canadian hospitals. Many of the affidavits submitted were statements by physicians attesting to the regularity in which they carried out the other EOLC practices. These affidavits described as well what the physicians believed to be the direct outcome of these practices: starvation, dehydration, respiratory suppression, and other physiological changes leading to death. As one physician wrote, “I was also required to withhold or withdraw life sustaining treatment…including the discontinuation of the use of a ventilator in circumstances where the withdrawal of such will certainly result in suffocation” (affidavit, Klein). Many of these physicians expressed incomprehension as to the logic of being allowed to perform these practices but not PAD, an incomprehension shared as well by many lay affiants. One retired urologist pointedly said that withdrawal of life-sustaining treatment used to be considered ethically unacceptable (Interviewee Syme). For this witness, historical developments in end-of-life care towards current ethical and legal acceptability of the other EOLC practices constituted evidence that patients already had the right to request medical assistance in dying. The legalization of PAD would thus be the logical next step in the evolution of EOLC. Our analysis of the data shows the proponents expending efforts to end the perceived hypocrisy of the law by: accentuating the physician’s role in the other EOLC practices, making visible the inequity in EOLC opportunities for patients, and pointing out the existing institutional capacity in EOLC decision-making.

The Physician’s Role in Hastening Death

In their discussion of the other EOLC practices, proponents placed great emphasis on the role of the physicians. Dying with Dignity (DWD), a national right-to-die organization, wrote that the “purported distinction [between the withholding and withdrawal of care and PAD] is unsustainable because current lawful end-of-life practices are not entirely passive” (factum). It argued that these practices “often involve the active participation of a physician (for example, to remove a feeding tube or ventilator), which… results in the patient's ultimate cause of death (e.g. starvation, dehydration or respiratory failure).” While the patient’s underlying medical condition was often discussed in relation to the suffering experienced by the patient, it was never invoked by the proponents as a cause of death when discussing the other EOLC practices. It was rhetorically important for the opponents to establish the EOLC practices as the patient’s cause of death.

Moreover, proponents argued that the actions of physicians would not only cause death but also *shorten the life of the patient*. This argument was most explicit in the proponents’ discourse on palliative sedation. Recall that healthcare practitioners were advised to consider the clinical decision to induce palliative sedation separately from the decision to remove artificial hydration and nutrition from the patient. We nonetheless observed a concerted effort on the part of the proponents to discursively bind the two practices together. In almost all instances during trial when palliative sedation was discussed, Joseph Arvay, the lead counsel for the claimants, would bring up the issue of the removal of hydration and nutrition as well. He first extracted concessions from the government’s expert witnesses that in clinical practice, the removal of hydration and nutrition would often follow the administration of sedatives. In one remark to a palliative care physician testifying for the government, he said, “you know, I'm just a simple lawyer. The simple point that I wanted to get from you, and I think you've given it, for whatever the reasons sometimes part of the intervention of palliative sedation is the discontinuation of nutrition and hydration, right?” (trial transcript). This concession then became the basis for another concession that he extracted from the opponents: that palliative sedation, *understood as the amalgamation of both sedation and the removal of hydration and* *nutrition*, would hasten the death of the patient. The following is taken from Arvay's cross-examination of the same palliative care physician:

> Counsel: [S]ometimes palliative sedation is administered as deep and continuous -- to place the patient into a deep and continuous state of unconsciousness and sometimes that happens when death is not imminent at least in the sense of days, but death may take one or two or even three weeks to occur. And in those circumstances when nutrition and hydration is withdrawn for whatever the reasons it's certain in those circumstances that palliative sedation will shorten life. That's obvious, right?
> Witness: Yes.

In this excerpt, Arvay is talking about palliative sedation in a very specific context: when a patient's life expectancy is greater than one week. The use of palliative sedation for patients who are not imminently dying remains controversial amongst clinicians and bioethicists (Cellarius, 2011). Proponents were evidently aware of this controversy and in *Carter*, we saw them exploiting it to their advantage. By discursively binding palliative sedation to the removal of hydration and nutrition and placing spotlight on its use on patients not imminently dying, proponents made it harder for the opponents to attribute the cause of death to the patient's underlying illness, thus making palliative sedation less distinguishable from PAD.

Inequity in End-of-Life Care

Proponents argued that the availability of the other EOLC practices as a form of medical assistance in dying for some patients created unacceptably unjust situation in end-of-life care for all patients. A strong example can be found in the proponents' discourse on withholding/withdrawal. One expert witness' involvement in the issue of PAD was, in fact, triggered by reflections on whom the 'benefits' of the practice of withholding and withdrawal of care were denied. Describing the insights gained during her experience as an internal medicine resident, she gave the example of a terminally ill patient on dialysis who could choose to hasten death by discontinuing the dialysis. She then “became aware that there was a group of patients who did not have that choice because they didn’t require dialysis…They were on no life-sustaining treatment and yet they had the same terminal illness in a sense and were suffering just as grievously. So I thought that wasn’t just and was the beginning of my feeling about [PAD]” (trial transcript). This witness thus framed the other practices not primarily or solely as therapeutic practices to relieve suffering (or avoid further suffering in cases of withholding and withdrawal of life support) but as medical instruments to accelerate dying. Viewed in this way, the other practices became a form of medical privilege that accrued only to some patients.

The impugned law that allowed physicians to provide medical assistance to hasten death in the forms of withholding or withdrawal of life-sustaining treatment, palliative sedation, and opioids use was then, for the proponents, discriminatory towards a certain group of people: those who were suffering unbearably from a medical condition and yet unable to avail themselves of any of the other EOLC practices. Gloria Taylor, one of the claimants, wrote: “I also cannot understand why it is permissible for my friend, who is on kidney dialysis, to say ‘enough is enough’ and make the decision to die. I cannot understand why the law respects his wish and decision to die, but does not do the same for me. We are equally competent” (affidavit). For Taylor, the law unfairly and illogically discriminated against people like her. The decriminalization and legalization of PAD was thus seen as a form of ‘affirmative action’ for suffering individuals like her; it would remedy the current imbalance in opportunities in end-of-life care. As one neurologist argued, in order to “treat these patients [who are not dependent on life support] *equitably* and compassionately we should offer physician-assisted dying as it is their only option to hasten death" (emphasis added, affidavit).

Institutional Capacity for End-of-Life Care Decision Making

One way proponents collapsed the boundaries between PAD and the other EOLC practices was by arguing that the "risks of decisional vulnerability" that attended to the former were the same that attended to the latter. That is, proponents argued that the factors that would affect a patient's competence in making an informed request for PAD would be the same factors implicated in decision-making involving the other practices. One issue that received considerable attention in *Carter* is the potential impact of depression on patient's competence. In his affidavit, one physician wrote:

> If a person is suffering from severe depression to the point where they are incompetent to make medical decisions or to the point where they are actively suicidal, they may be incompetent to make medical decisions at all, including decisions in regards to refusal of care, withdrawal of care or seeking physician assisted dying…In my view, risk of incompetence due to depression would be the same whether an individual was making a decision, on the one hand, to refuse or direct the withdrawal of life-sustaining treatment or to consent to terminal sedation, or on the other to request physician-assisted suicide (affidavit, Smith).

For this expert witness, depression would affect a patient's global competence in medical decision-making, regardless of whether the practice being considered was PAD or one of the other EOLC practices. Therefore, coming to an informed decision to request PAD for competent patients was, for the proponents, no different from coming to an informed decision with regards to any of the other EOLC practices.

Proponents further argued that the institutional capacity (i.e., the capacity of Canadian medicine as a social institution) to assess the risks associated with PAD already existed because these were the risks that Canadian physicians were already accustomed to dealing with when making decisions involving the other EOLC practices. In her address to the SCC Justices, one of the counsels for the claimants stated that people “who want to withdraw their ventilator so that they can die may be elderly, they are certainly disabled by whatever is making them ill enough to need the ventilator. They may also have a pre-existing disability, they may also be impaired by depression” (trial transcript). She added that these “are things that Canadian physicians already deal with in end-of-life decision making and essentially what [the trial judge] was saying the *same test, same consequences, same factors*” (emphases added, trial transcript). Thus, to imply that abuse was likely to occur if PAD were to be legalized was to impugn the credibility of Canadian physicians and their capacity to make appropriate EOLC decisions. The proponents pointed out that there was no regulatory regime that oversaw the other EOLC practices,[1] and yet, “presumably due to the professionalism of Canadian physicians, there is no evidence to suggest that many wrongful deaths occur in the context of these other end-of-life practices” (factum). In fact, for the proponents, wrongful deaths from PAD would be even less likely to occur because legalization would impose a stringent control mechanism that the other practices would not be subjected to.

DISCUSSION

In this article we have shown how stakeholders in a landmark PAD litigation debated the ethical distinction between PAD and the practices of withholding and withdrawal of life-sustaining treatment, palliative sedation, and opioid use. Opponents defended the orthodox positions in bioethics and law that there were boundaries between PAD and those other EOLC practices, arguing that in the latter the physician’s intent to kill was and *must be* absent; that those practices did not cause death if practiced correctly; and that they were concordant with the ‘natural’ process of dying. Proponents, for their part, rejected the ethical distinction between PAD and the other EOLC practices, arguing that for all intents and purposes they were all variants of the same practice. In their discourse, proponents emphasized the physician’s active, rather than passive, role in the other EOLC practices; made visible what they perceived to be inequality in EOLC for patients; and pointed out the robust infrastructural capacity in EOLC decision-making that already existed in Canadian medicine. Our analysis of the ‘border disputes’ between the stakeholders contributes to studies in sociologies of bioethics and empirical bioethics that reveal how actors produce and reproduce ethical ideas and positions in concrete, empirical situations that are politically and legally consequential.

Opponents naturalized the other EOLC practices while simultaneously constructing PAD as an artificial, manmade intervention into the life process. In appealing to the ‘natural,’ the opponents were recycling the nature/culture binary commonly found in bioethics and legal discourse on death. McGee (2005, 382-383), for example, defends the practice of withdrawal of life-sustaining treatment as distinct from euthanasia, writing that “euthanasia interferes with nature’s dominion, whereas withdrawal of treatment restores nature to her dominion after we had taken it away when artificially prolonging the patient’s life.” The opponents’ discursive move in this regard was meant to diminish or do away with any trace of human activity in the case of the other EOLC practices while emphasizing it in the case of PAD. As Hopkins (1997, 30) has trenchantly observed, calling something ‘natural’ has “an important discursive effect, separating out some phenomena as prior to medical action…The discursive space created is a centrally moral space for perceived as an area where humans are not acting, it is also therefore an area where human moral responsibility cannot obtain.” Opponents’ discursive move here was surely shaped by the legal construct of ‘natural death,’ as in Dufour J.’s formulation of Nancy B.’s death from ventilator withdrawal as a “natural death,” unlike suicide or homicide [B(N) v. Hôtel Dieu de Qué (1992) A.Q. no 1]. Thus, opponents’ naturalization of the other EOLC practices must be understood within a social context whereby *which* death was called ‘natural’ was legally consequential. The opponents’ position was perhaps most persuasive with regards to withholding and withdrawal of life-sustaining treatment and much less so with the other practices. We think this was one reason why proponents made such a concerted effort to discursively bind the practice of palliative sedation to the removal of hydration and nutrition. This discursive move was meant to highlight not only physician’s active participation in palliative sedation but also attributing it as the cause of the patient’s death. For the proponents, death from the other EOLC practices – like in the case of PAD – was anything but natural.

Opponents also drew the boundaries between PAD and the other EOLC practices along the line of physician’s intent. According to opponents, when carrying out the other EOLC practices, physicians might *foresee* the patient’s death but not *intend* it. Magnusson (2006, 563) has observed that “we impute intention for the foreseen consequences of socially worthless actions when there is a public interest in holding a person morally responsible for those consequences.” Claiming that death was merely foreseen in those practices, but not intended, was a way for the opponents to “absolve [a physician] from any moral responsibility for adverse outcomes” (Magnusson, 2006, 563). More importantly, this discourse reflected the traditional ethical belief that unilaterally prohibited intentional killing by physicians. The opponents’ distinction of PAD from the other practices along the line of physician's intent, then, was shaped by and at the same time reproduced the Hippocratic ideal of physicianhood.

The opponents further argued that, if practiced correctly, other EOLC practices should not and did not necessarily lead to patient's death. For the opponents, this 'right' way of doing EOLC could only come about through socialization in palliative care and experience with its technologies and knowledge, which purportedly would allow for medical interventions without leading to death. Palliative care, as a social movement, has long defined itself as a healthcare approach that "intends neither to hasten nor postpone death" (World Health Organization (WHO), 2016). Insofar as withholding and withdrawal of life-sustaining treatment, palliative sedation, and opioid use were now considered standard palliative care interventions, they could not and were not seen by the opponents – especially those who self-identified as palliative care professionals – to be causing or hastening death. Doing so would challenge the very identity around which palliative care has constructed itself. Zerubavel (1996) points out that when actors carve reality into distinct entities, they do so not as individuals but as members of a particular thought community. This particular finding, then, suggests that the opponents' discourse was strongly shaped by the ideologies of the palliative care community. Moreover, the establishment of epistemic authority is an important outcome of boundary work (Gieryn, 1983; 1999). The distinctions drawn by the opponents therefore had the effect of discriminating those with palliative care expertise from those without.

Proponents, on the other hand, argued that because the other EOLC practices were already legally and ethically accepted in Canada, an inequity in EOLC for suffering patients arose for those whom, for whatever reason, could not avail themselves of any of the other EOLC practices to hasten their death. They argued as well that the risks of decisional vulnerability in end-of-life decision-making were the same for both PAD and the other EOLC practices, and that Canadian physicians already had the expertise to assess these risks through their experience with the other practices.

Some commentators have hypothesized that the gradual progression towards the ethical and legal acceptability and growing use of the other EOLC practices – withholding and withdrawal of life-sustaining treatment in particular – may have inadvertently aided the right-to-die movement (e.g., Emanuel, 1994; Tierney, 2010). As early as 1973, Williams (1973, 68) wrote that "[a] toehold for euthanasia is provided by the practice of letting die, or what is called passive euthanasia." Joseph Fletcher (1987), a former president of the Euthanasia Society of America, has admitted that part of the original goal of his organization was to push for the public acceptance of withholding and withdrawal of life-sustaining treatment at a time when such practice was not yet widely accepted. The findings of our study provide support for this hypothesis. Additionally, our analysis revealed one mechanism by which proponents used the other EOLC practices as a "toehold" for the legalization of PAD: proponents used the acceptability and availability of those practices to point out what they believed to be the perceived hypocrisy and discriminatory effect of the impugned law. They also used those practices to make visible the institutional capacity in EOLC decision-making that existed already in Canadian medicine. Legalization of PAD would, according to the proponents, posed no greater threat to vulnerable patients than that which already existed with regards to the other practices.

The findings of our study carry implications for understanding the constraints on the right-to-die movement elsewhere. The ethical and legal landscape with regards to the other EOLC practices varies radically by country. In Israel, for example, physicians are obliged to persuade patients to accept life-supporting treatment and may not respect a competent patient's request to withdraw it (Schicktanz et al., 2010). Our analysis, if correct, suggests then that the right-to-die movement may be less likely to succeed in places where there is no widespread legal and ethical acceptability of the other EOLC practices.

In the final analysis, we argue that the border disputes between the proponents and opponents of PAD point to the complexity that is inherent in enacting any medical practice at the end of patient's life. Pool (2014, 155), in his hospital ethnography of euthanasia in the Netherlands, writes that "[a]lthough an unambiguous and generally accepted definition of euthanasia is in many respects desirable, particularly with regard to (legal) control, it can also lead to problems if it is interpreted as a reflection of clinical practice" (p. 155). He further argues that "there is a whole range of life-shortening actions by physicians that can be interpreted in different ways, and it is in the participants' discourse - how they speak and write about their actions - that these actions are defined as euthanasia or normal medical practice" (p. 160). Such cleavages as imparted by the various labels used – be it euthanasia, withholding or the withdrawal of life-sustaining treatment or terminal sedation – are but artificial divisions that do not correspond to any lines that can be 'naturally' discerned in in the act of enacting the practice. This is not to say that the discursively constructed distinctions between PAD and the other practices by the opponents do not have real, material effects. Indeed, the fact that they do is, in our opinion, the very reason behind the border disputes.

NOTES

[1] This is no longer true in Canada: Quebec's *An Act Respecting End-of-Life Care* established, among other things, a regulatory regime for 'medical aid-in-dying" and palliative sedation. The law came into force in December 2015.

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CHAPTER 5

CONCLUSION

The overarching aim of this thesis was to analyze the central phenomena that constitute the contemporary debate over the decriminalization and legalization of physician-assisted dying (PAD) in Canada. The landmark court case of *Carter v. Canada*, resulting in the invalidation of the Criminal Code prohibitions on PAD by the Supreme Court of Canada (SCC) in 2015, provided an empirical opportunity for such an analysis. Three inter-related but distinct research questions motivated my analysis. In the first article, I ask how participants of the case used the new knowledge from the permissive jurisdictions of PAD around the world. In the second, I ask how proponents construct the relationship between 'suffering' and the role and place of medicine at the end of life. In the third, I investigate the dispute among the participants on the ethical distinction between PAD and other end-of-life care practices. The findings that I detail in each article have implications for our understanding of how palliative care has shaped the contemporary debate on PAD in Canada, how the right-to-die movement is imbricated with the medicalization of death and dying, and, finally, how the moral and legal status of EOLC practices of a particular jurisdiction matters for the debate on PAD.

RESEARCH SUMMARY AND SOCIOLOGICAL IMPLICATIONS

The first article examines the role that new, largely empirical, knowledge from permissive jurisdictions played in *Carter*. Despite PAD being a topic that has been debated since ancient times, the medico-legal regimes of PAD are relatively recent phenomena that provided participants of the case new evidence to draw upon. The proponents and opponents used the newly acquired knowledge to construct cultural meanings of PAD in widely divergent ways around three central themes: 1) whether patients who sought PAD were suicidal; 2) whether physicians who enacted PAD were competent in palliative care; and 3) whether state oversight of PAD could provide adequate safeguards against abuse. The opponents constructed PAD as a practice accessed by suicidal patients, carried out by uncaring physicians with inadequate expertise in palliative care, and loosely regulated through a fallible regime. The proponents countered by constructing PAD as a practice borne out of a patient's rational choice, performed by physicians within an environment whereby palliative care specifically and end-of-life care (EOLC) in general had improved since legalization, and was tightly regulated through a regime where the participants functioned as sentries overseeing each other's actions. Proponents thus used the new knowledge from the permissive jurisdictions to evoke cultural expectations of what it meant to die a good death in this day and age (i.e., the ideology of 'the good death'). I argue that the proponents' success in this case contributed to the production and reproduction of a historically specific cultural script that made death by way of PAD 'culturally appropriate' (Timmermans, 2005).

In the second article, I analyze proponents' articulation of suffering with the role and place of medicine at the end of life. Much of the literature on PAD thus far has focused on the 'autonomy' arguments made by the proponents. Focusing instead on the proponents' discursive mobilization of 'suffering' proved useful for understanding how the medicalization of death and dying was imbricated with the right-to-die movement. I found that the proponents laid much of the blame for end-of-life suffering on mainstream curative medicine, faulting its moral imperative to prolong life and embrace of death-denying professional culture. Proponents also emphasized the limitations of palliative care and boldly claimed that, in some instances, palliative care interventions could produce additional suffering. They were not, however, rejecting the place of medicine at the end of life. Indeed, they insisted on the involvement of physicians and other healthcare professionals in assisted dying. They argued that medical regulation of assisted dying would be therapeutic for patients even if the process did not culminate in the administration of lethal medication. This particular finding suggests that far from being seen as a constraining framework, the medicalization of death and dying had been used by proponents for constructive ends. I argue that proponents' articulation of suffering with the role and place of medicine at the end of life must be understood as a discourse through which one configuration of EOLC came to be accepted and another rejected, a discourse that did not at all challenge the larger framework of the medicalization of death and dying in the 21st century.

While there has been much discussion in the bioethics and legal scholarship on the ethical distinction between PAD and the practices of withholding and withdrawal of life-sustaining treatment, palliative sedation, and opioids use, less attention has been paid to how the stakeholders debate this distinction in the context of a successful social movement to decriminalize or legalize PAD. The third article thus looks at the ways in which opponents in *Carter* rigorously policed the boundaries between PAD and the other EOLC practices as well as the proponents' dialectical strategy in collapsing those boundaries. The opponents argued that physician's intent to kill must not be present in the other EOLC practices to distinguish them from PAD; that those practices did not cause death if carried out correctly; and that they were concordant with the 'natural' process of dying. The proponents, on the other hand, emphasized physicians' active role in the other EOLC practices, making visible what they perceived to be an inequality in EOLC among patients, and pointed out the robust institutional capacity in EOLC decision-making that already existed in Canadian medicine. Proponents thus used the ethical and legal acceptability of the other EOLC practices as a means to push for the acceptance of PAD. I argue that these ‘border disputes’ between the opponents and proponents point to the complexities inherent in enacting any medical practice at the end of a patient’s life and the discursive nature of the different categories of EOLC practices.

My research has several implications for our understanding of the contemporary debate on physician-assisted dying (PAD). First, my thesis builds on studies that show how discursive representations of PAD are “cultural constructions and have evolved through the years depending on the cultural and societal environment” (Jylhänkangas et al., 2014, 355). The findings of this research, especially those detailed in the first article, stand in contrast to the claim that “the arguments for or against euthanasia have changed neither in form nor substance in almost 120 years” (Emanuel, 1994, 801). My analysis reveals that one of the most important differences in the contemporary debate on PAD is the emergence and rise of the hospice and palliative care movement. Palliative care as a distinct body of healthcare knowledge, practices, and professions did not exist a century ago. Palliative care practitioners have hitherto successfully set the medical standards for the contemporary ‘good death.’ They have, therefore, colonized the field of EOLC to such an extent that their rhetoric could not be unequivocally rejected and had to be taken seriously and then refuted by the right-to-die movement, thus inflecting the contemporary debate on PAD in a historically distinct way.

Second, my research counters the popular belief, within and outside of academia, that the right-to-die movement is a demedicalizing movement. In the second article, I show how the proponents of PAD rejected some aspects of the medicalization of dying and yet paradoxically insisted on the medical regulation of assisted dying. Thus, framing the right-to-die movement simply as a means for patients to gain control from the medical establishment over their dying experience would be inaccurate. As Norwood (2009) argues, many have made the incorrect assumption that it was the laissez-faire attitude of the Dutch that allowed for the emergence of a euthanasia regime in that country. In fact, the regime, in the Netherlands and now in Canada, allows for a high degree of state and medical control over the dying process. The *Carter* case is thus a fitting example of what Turner (1995) calls the 'Foucault paradox:' the contradiction between the demand for individual rights to autonomy and social surveillance inherent in the aspirations of many health social movements. That is, the growing call for equality of health outcomes (or, in the case of the right-to-die movement, death outcomes) cannot be accomplished without greater state involvement and medical interventions on individual lives and bodies.

Finally, my research shows how what I am calling the 'moral and legal ecology of end-of-life care practices' of a particular jurisdiction matters for the debate on PAD. In the third article, I discuss how the proponents' discourse on the boundaries between PAD and other EOLC practices whose outcome is likely to be death helped contribute to their victory in the Canadian court. The social movement to construct PAD as a social problem thus far has emerged in Western, developed countries only. There is a facile assertion often made to explain this observation: in less developed countries, individuals are often not in a position to make decisions about their future (hence, about their dying) due to the precariousness of their living conditions (see, for e.g., Dickinson et al., 2005). The fact that this assertion is also true for many social movements in the West, not just the right-to-die movement, means that it cannot not adequately explain how and why PAD emerged as a social problem in many Western, developed societies. In many developing countries such as Turkey, India, or Kenya, the cessation of life-sustaining treatment is legally prohibited (Blank, 2011). In contrast, societies that have been embroiled in the controversies to legalize PAD have accepted what Tierney (2010) calls 'medicalized suicide' in the form of the right to refuse life-prolonging treatment or withdraw it. Thus, as Tierney argues, within such a society, the widespread acceptance of the other EOLC practices actually contributes to the growing expectation of a right to PAD, an expectation that we see the proponents in *Carter* exploiting to their advantage. In this way, my research has shown how the legal and ethical status of the other EOLC practices at a given point in time may help the proponents in a Western, developed society advance their cause.

LIMITATIONS

The biggest limitation of this research is that I was only able to observe what happened on the 'front stage' of the case. That is, I was only able to collect data on the publicly observable events of the case (i.e., the trials) as well as on the documents generated by the participants of the case themselves. Even my in-depth interviews with participants occurred after they had developed their arguments and submitted their documents. I had no access to the strategic planning and 'back-stage' communication within constituencies and between the participants that could help explain precisely why participants – especially the claimants and the government – chose to frame certain issues in particular ways. For this reason, this research is better able to answer questions of 'how' (i.e., questions relating to descriptions of processes) than 'why' (i.e., questions about causality). Although in many places I make inferences as to what I believe could plausibly explain the participants' choice of argumentation, further research is needed to verify these inferences. Methodological innovations from the field of science and technology studies (STS) could serve as inspirations. What is needed to supplement this research, in my opinion, is a 'law in action' research akin to the 'science in action' research that revolutionized STS in the 1980s and 1990s (see, for e.g., Latour, 1987; Latour & Woolgar, 1979). STS researchers were able to gain intimate access to the private spaces of scientists (e.g., laboratories) and therefore observed directly the production of scientific discourses. Similarly, researchers that are able to observe directly how the discourses in a PAD debate are *prepared and produced* before being released publicly for consumption, negotiation, and re-production in the legal and political arena would advance our understanding of the contemporary debate on PAD.

Another aspect of this research that could be perceived as a limitation is the legal context within which the data were produced. Given that the aim of the research is to gain insights into the central phenomena that constitute the contemporary debate over PAD, one might reasonably ask to what extent a legal case such as *Carter* is well-suited to accomplish this aim. This question is predicated upon the assumption that the debate on PAD can unfold in and overlap across multiple arenas: in the media, for example, or in bioethics scholarship. I argue that because the debate on PAD is ultimately about *the decriminalization and legalization* of PAD, priority should be granted to understanding the debate within the legal and political arena, rather than elsewhere. To be sure, how the debate unfolds elsewhere has implications for how it unfolds in the legal arena – witness the use of bioethics ideas and principles by *Carter* participants – and vice versa, but it is the success or failure of the proponents and opponents in persuading powerful legal and political actors of their arguments that is, in the final analysis, consequential for society as a whole.

FUTURE DIRECTIONS FOR RESEARCH

I began this thesis with the caveat that my objective in studying *Carter* was not to generalize my findings to other right-to-die movements. Rather, I was more interested in exploring the dynamics of a particular case and what they could tell us about different aspects of the debate on PAD and how they might lead to decriminalization of PAD within the Canadian context. One area for future research, therefore, would be to do a comparative (historical) study of the different cases that that are currently unfolding or that have recently unfolded in many different jurisdictions in the world. It is important that such a comparative study includes cases whereby the proponents *fail* in their attempts to decriminalize or legalize PAD. One objective of this study would be to identify which of the participants' practices and aspects of their sociopolitical environments contribute decisively to either the success or failure of the movement.

The implementation of the new law on 'medical assistance in dying' in Canada in response to *Carter* opens up further avenues for research. Here, I suggest two potentially fruitful ones. The new Canadian law is unique from a global perspective because it empowers nurse practitioners, in addition to physicians, to administer the lethal medication to patients.[1] Although the laws in other permissive jurisdictions do not confer similar authority to nurses, recent studies suggest that nurses in those places nonetheless participate actively in the assisted dying process. Nurses help patients understand medical concepts; they are often present during assisted dying conversations between physicians and patients where they act as translators between the two parties; and they serve as conduits between patients and families (Denier et al., 2010; Dierckx de Casterlé et al., 2010). A new research endeavour would build on these studies and investigate how the new law impacts Canadian nurse practitioners specifically and the nursing profession in general. Another fruitful avenue for research would be to investigate how the implementation of 'medical assistance in dying' impacts the practice of palliative sedation in institutional settings. Seymour et al.'s (2007) research on the euthanasia practice in the Netherlands suggests that palliative sedation emerged as a preferred alternative to euthanasia for many healthcare practitioners after legalization. In this way, palliative sedation acquired the status of "the 'third way' between the polarised pro- and anti-euthanasia stances of the past" (Seymour et al., 2007, 1684). Future research should investigate if a similar phenomenon is taking place in Canada. The province of Quebec in particular would make for an interesting setting for such a study as it is the only jurisdiction in the world thus far to have instituted a regulatory regime of palliative sedation. The ways in which this regulatory regime intersects with the medical assistance in dying regime would be one of the objectives of such a study.

CONCLUDING REMARKS

In this thesis, I have analyzed the dynamics of the landmark court case of *Carter v. Canada* in order to understand some of the central phenomena that constitute the contemporary debate on PAD. *Carter* has ushered in a new era in end-of-life care for Canadians. I hope this thesis can serve as a resource for those interested in learning more about this key event in the history of death and dying in Canada. Further, I have no doubt that *Carter* and the legalization of 'medical assistance in dying' will have ripple effects beyond the borders of

Canada, just as other permissive jurisdictions have been an important condition of possibility for the Canadian case.

NOTES

[1] The conferral of authority on nurse practitioners to administer the lethal medication could explain the federal government's choice of referring to the practice as 'medical assistance in dying' rather than 'physician-assisted dying,' the term that was used in *Carter*.

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APPENDIX A

The Engaged Sections of the Canadian Charter of Rights and Freedoms in *Carter v. Canada* and *Rodriguez v. British Columbia*

The Carter claimants challenged the constitutionality of the impugned provisions of the Criminal Code (see Appendix B) under sections 7 and 15 of the *Charter*. In contrast, twenty years prior, Sue Rodriguez challenged section 241(b) of the Criminal Code under sections 7, 12, and 15 of the *Charter*. Taken verbatim from the *Charter* (Government of Canada, 1982), the engaged sections were as follows:

Section 7:
Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

Section 12:
Everyone has the right not to be subjected to any cruel and unusual treatment or punishment.

Section 15:
(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.
(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

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APPENDIX B

The Impugned Provisions of the Criminal Code in *Carter v. Canada*

The Carter claimants challenged the constitutionality of sections 14, 21, 22, 222, and 241 of the Criminal Code. The claimants argued that these sections collectively prohibited 'physician-assisted dying.' Taken verbatim from the then-Criminal Code (Minister of Justice of Canada, 1985), the impugned provisions were as follows:

<u>Section 14:</u>
No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted on the person by whom consent is given.

<u>Section 241:</u>
Every one who
(a) counsels a person to commit suicide, or
(b) aids or abets a person to commit suicide,
whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years.

<u>Section 21:</u>
(1) Every one is a party to an offence who
    (a) actually commits it;
    (b) does or omits to do anything for the purpose of aiding any person to commit it; or
    (c) abets any person in committing it.
(2) Where two or more persons form an intention in common to carry out an unlawful purpose and to assist each other therein and any one of them, in carrying out the common purpose, commits an offence, each of them who knew or ought to have known that the commission of the offence would be a probable consequence of carrying out the common purpose is a party to that offence.

<u>Section 22:</u>
(1) Where a person counsels another person to be a party to an offence and that other person is afterwards a party to that offence, the person who counselled is a party to that offence, notwithstanding that the offence was committed in a way different from that which was counselled.
(2) Every one who counsels another person to be a party to an offence is a party to every offence that the other commits in consequence of the counselling that the person who counselled knew or ought to have known was likely to be committed in consequence of the counselling.
(3) For the purposes of this Act, "counsel" includes procure, solicit or incite.
Section 222:

(1) A person commits homicide when, directly or indirectly, by any means, he causes the death of a human being.
(2) Homicide is culpable or not culpable.
(3) Homicide that is not culpable is not an offence.
(4) Culpable homicide is murder or manslaughter or infanticide.
(5) A person commits culpable homicide when he causes the death of a human being,
  (a) by means of an unlawful act;
  (b) by criminal negligence;
  (c) by causing that human being, by threats or fear of violence or by deception, to do anything that causes his death; or
  (d) by wilfully frightening that human being, in the case of a child or sick person.
(6) Notwithstanding anything in this section, a person does not commit homicide within the meaning of this Act by reason only that he causes the death of a human being by procuring, by false evidence, the conviction and death of that human being by sentence of the law.

REFERENCE

Minister of Justice of Canada. (1985). *Criminal Code*, R.S.C., 1985, c. C-46 C.F.R.

APPENDIX C

List of Interveners in *Carter v. Canada*

Judiciary Level	Interveners
B.C. Supreme Court	Farewell Foundation for the Right to Die
	The Christian Legal Fellowship
	Canadian Unitarian Council
	The Euthanasia Prevention Coalition and The Euthanasia Prevention Coalition - British Columbia
	Ad Hoc People with Disabilities Who are Supportive of Physician-Assisted Dying
B.C. Court of Appeal	Alliance of People with Disabilities Who are Supportive of Legal-Assisted Dying Society
	The Canadian Unitarian Council
	The Farewell Foundation for the Right to Die
	The Christian Legal Fellowship
	The Evangelical Fellowship of Canada
	The Euthanasia Prevention Coalition and The Euthanasia Prevention Coalition - British Columbia
	The Council of Canadians with Disabilities
	Canadian Association for Community Living
Supreme Court of Canada	Alliance of People with Disabilities Who are Supportive of Legal-Assisted Dying Society
	Canadian Civil Liberties Association
	Canadian HIV/AIDS Legal Network and the HIV & AIDS Legal Clinic Ontario
	Canadian Unitarian Council
	Criminal Lawyers Association (Ontario)
	Dying with Dignity
	Farewell Foundation for the Right to Die and the Association québecoise pour le droit de mourir dans la dignité
	Evangelical Fellowship of Canada
	Euthanasia Prevention Coalition and Euthanasia Prevention Coalition - BC
	Association for Reformed Political Action Canada
	Catholic Civil Rights League and Faith and Freedom Alliance and the Protection of Conscience Project
	Catholic Health Alliance of Canada
	Christian Legal Fellowship
	Christian Medical and Dental Society of Canada and the Canadian Federation of Catholic Physicians' Societies
	Collectif des médicins contre l'euthanasie
	Council of Canadians with Disabilities and the Canadian Association for Community Living
	Canadian Medical Association
	Attorney General of Ontario
	Attorney General of Quebec

[1] *Carter* began in the British Columbia Supreme Court in 2011 where Smith J. found for the plaintiffs, a decision that was later overturned by the British Columbia Court of Appeal in 2013. The SCC granted claimants leave to appeal and heard the case on 15 October 2014. In the aftermath of the ruling, the federal government was given 12 months to amend the Criminal Code before the impugned prohibitions become null and void in the context of PAD.

[2] This is not to say that the debate on PAD did not continue in other spheres of Canadian society. Since 1993, six private members' bills to legalize PAD had been introduced in Parliament.

[3] These jurisdictions are as follows: The American states of Oregon, Washington, Montana, Vermont, New Mexico and California, the Northern Territory of Australia (later overturned by Canberra), Colombia, the Netherlands, Belgium, Luxembourg, and Switzerland.

[4] We recognize differences in the processes that produced the legal, documentary data and the interview data as well as the different types of sociological claims that could be made with each type of data. In this study, however, the in-depth interviewing was designed from the outset to 'speak' directly to the legal data. The interview guide for each participant was tailored according to that participant's legal data (i.e., the participant's factum, affidavit, or examination transcript). The interviews thus provided not only depth and nuance to the legal data, but another discursive opportunity for the participants to construct the reality of PAD in particular ways.

[5] Only PAS is legal in Oregon and Washington. Colombia has euthanasia only. In Switzerland, assisting a person to commit suicide is not a crime so long as it is done for unselfish reasons. The Netherlands and Luxembourg have legalized both euthanasia and PAS. In Belgium, while the law explicitly mentions euthanasia only, the oversight body has allowed for PAS.

[6] To stay close to the data, we use the term 'Canada' here to refer to the opponents (i.e., the Attorney General of Canada along with its witnesses and interveners supporting its position).

[7] 'Claimants' refer to the proponents (i.e., the plaintiffs along with their witnesses and interveners supporting their position).

[8] This is not to imply that our study participants did not make distinctions between euthanasia and PAS. All of the actors involved in the case recognized the practical and policy distinctions between euthanasia and PAS.

[9] Balfour Mount is widely acknowledged to be a palliative care pioneer in North America (Youk, 2004). In 1974, he established one of the first palliative care units in Canada at the Royal Victoria Hospital, part of McGill University Health Centre in Montreal. In Canada, palliative care exists as an official sub-specialty of medicine.

[10] In their decision, the SCC Justices agreed with the findings of Smith J., the trial judge, stating that she "made no palpable and overriding error in concluding, on the basis of evidence from scientists, medical practitioners and others who are familiar with end-of-life decision-making in Canada and abroad, that a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error" [Carter v. Canada (Attorney General) 2015 SCC 5, 468 N.R. 1, (Can.), 10].