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## Suffering and medicalization at the end of life: The case of physician-assisted dying

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## 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.

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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

## 1. 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

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'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*.

## 2. Background

### 2.1. Contextualizing *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.

### 2.2. 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 "technoscience 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., neurovegetative state) and at the same time remade the moral frameworks at the end of life (Kaufman, 2005; Kaufman and 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, p. 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, p. 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 “prolongevity” and which they view as producing more harms than benefits to persons at the end of life.

### 2.3. 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, 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 and Seymour, 1999, p. 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, p. 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.

### 2.4. 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 \(2015, p. 6\)](#) 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” (p. 76) and “has served as a symbolic critique of how dying people are managed in other medical settings” (p. 121). Others, however, see palliative care as contributing to the medicalization of dying. [Broom \(2015, p. 12\)](#), 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 \(2009, p. 20\)](#) 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 \(1999, p. 64\)](#), 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 [Connolly \(1998\)](#), 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.

## 3. 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 analyze consist of all of the legal artefacts generated by the case (i.e., affidavits, trial transcripts, factums, court decisions), all amounting to over 4000 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™. 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 and 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, p. 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, p. 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.

#### 4. 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.

##### 4.1. 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.

#### 4.2. 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, Arvey 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 Arvey 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 organisation, 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.

#### 4.3. 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 and 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 diarrhoea. 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.

#### 4.4. 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). On 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).

## 5. Discussion

Much of the research on the right-to-die movement focus 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, p. 288). This article asks instead how PAD proponents articulate suffering with the role of medicine at the end of life. McNerney (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, p. 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, p. 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 mobilized 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 and 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 and 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, p. 30). In other words, PAD practices “are the instruments that promote the ‘demedicalization’ of death” (ibid.). Our analysis shows how such 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 and 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, p. 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 on 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 (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, p. 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 and Strauss, 1966, 1980; Halper, 1979; Illich, 1976; IOM, 2014; McNamara and 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 other 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, p. 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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