



# 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

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