End-of-Life Liberty in Canada and the United States: Comparative Law and Policy Analysis

Project Description for a Fulbright Canada Research Chair in Health Law, Policy & Ethics at the University of Ottawa (9422-CA)

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Introduction

My Expertise in End of Life Liberty

Everybody dies. Unfortunately, not everybody dies well. For more than a decade, I have worked as one of the most influential writers on end-of-life law, ethics, and policy. I rank among the top-20 most cited health law scholars in the United States, with over 200 publications in leading medical journals, bioethics journals, and law reviews. I co-author the definitive treatise, *The Right to Die: The Law of End-of-Life Decisionmaking*, and I run the *Medical Futility Blog* (with over four million page-views). Both hospitals and families have retained me as an expert witness when they litigate end-of-life healthcare issues in the courts. And I have worked as a consultant for word-class organizations like the National Academy of Medicine, American Bar Association, American Thoracic Society, and Hastings Center.

While my primary discipline is law, I engage with an international and multi-disciplinary audience, writing and speaking for clinicians, bioethicists, lawyers, patients, and families. My ultimate objective is practical. I assist lawmakers, professional societies, and institutional policy drafters, so that they can safely expand options and improve care for patients.

Ottawa's Unique Advantages

Canada has more meaningfully grappled with increasingly pressing end-of-life liberty issues in its courts, legislatures, and other policymaking bodies. Much of this experience can serve as lessons for the United States, as the two countries share similar principles of medical jurisprudence and

ethics. Furthermore, given the overlap of U.S. and Canadian interests and approaches to health law and bioethics, this project will benefit both Canadian and U.S. lawmakers.
Ottawa is a uniquely advantageous location to study end-of-life healthcare policy. In addition to the Centre for Health Law, Policy & Ethics (which itself includes deep faculty expertise on end-of-life policy), the capital city hosts the national Parliament, the Supreme Court, and other key institutions that grapple with these issues. Three end-of-life issues are especially relevant for both countries in the early 2020s: (1) medical aid in dying, (2) medical futility, and (3) brain death.

Medical Aid in Dying

Background

United States. Medical aid in dying (MAID) is not yet legally available in 46 of 56 U.S. jurisdictions. But its legal status has been in a state of rapid change across the country over the past decade. Before 2008, MAID was legal only in Oregon. Today, it is explicitly lawful in ten U.S. jurisdictions (CA, CO, DC, HI, ME, MT, NJ, OR, VT, WA). Moreover, the rate and pace of legalization has been accelerating. Three MAID jurisdictions enacted their statutes within only the past two years. Moreover, there are widespread and ongoing legislative and judicial efforts to legalize MAID in more than thirty other states.

Despite all this activity, MAID in the United States is still anchored in a model that was designed more than 25 years ago. Most notably, all U.S. statutes require (among other things) both (1) that the patient has a prognosis of six months or less and (2) that the patient self-ingest the medication. These and other criteria materially limit access to MAID and reduce its safety.

Canada. In contrast, Canada has substantially advanced MAID access and safety in at least three ways. First, it is available in all provinces. Second, the law does not impose any strict temporal eligibility requirements. Third, almost all Canadian MAID is directly administered by clinicians, reducing the risk of adverse outcomes.

Furthermore, Canada is expanding even further. Not only is there no strict temporal requirement but also two MAID court cases seek to establish that requiring death be "reasonably foreseeable" is too restrictive and violates patients' constitutional rights. These cases are headed to the Supreme Court of Canada (*Lamb v. Canada* and *Truchon & Gladu v. Canada*). Meanwhile, the Council of Canadian Academies has issued reports that explore expanding MAID access even further, by making it available to minors and through advance requests.

My Fulbright Research Project

In my writing and presentations, I already synthesize and analyze lessons between Canada and the United States (http://thaddeuspope.com/maid/articles.html). For example, I was recently invited to deliver a plenary talk at the Fourth Annual Conference of the Canadian Association of MAID Assessors and Providers (CAMAP). I also contrast Canadian experience in recent presentations

and publications, including for the National Academy of Medicine. Extended, on-the-ground discussions with academics and practitioners will enable me to expand this work.

Ottawa is the home of both the federal Parliament and the Supreme Court. As these lawmaking entities will be grappling with MAID in 2021, it is valuable experience to interview: (1) policymakers, (2) their staff, (3) litigating counsel, (4) clinicians, and (5) academics. As Canada recalibrates the balance between MAID access and safeguards, a careful and deep understanding of the debates will enable me to best identify and articulate lessons for legislatures in the United States. At the same time, I hope that my experience with MAID debates in the United States will enable me to offer some lessons for Canadian policymakers.

Medical Futility

Background

Families of patients in both U.S. and Canadian hospitals regularly ask clinicians to administer life-sustaining medical treatment for incapacitated, critically ill patients in situations where the treating clinicians judge such treatment as non-beneficial and inappropriately aggressive. These conflicts are widely referred to as "medical futility" disputes. A key question is whether and how clinicians can stop life-sustaining treatment (such as CPR, dialysis, mechanical ventilation, and nutrition & hydration) ***without*** family consent.

Medical futility conflicts are becoming more frequent and more litigious. For example, recent United Kingdom cases like Charlie Gard were litigated not only to the UK Supreme Court but also to the European Court of Human Rights. British families and clinicians continue to litigate these cases (*see, e.g.,* Alfie Evans and Tafida Raqeeb). While the UK is still debating solutions, at least it takes a uniform and consistent approach. In contrast, U.S. jurisdictions are taking varying approaches. Some have enacted Simon's Laws that prohibit withholding or withdrawing life-sustaining treatment without consent. Other jurisdictions (like CA, TX, and VA) have enacted laws that specifically permit it.

The oldest and most well-known U.S. dispute resolution mechanism for medical futility disputes is the Texas Advance Directives Act. But TADA is under attack. First, the Texas state legislature has repeatedly amended and narrowed the law over the past few years. Second, litigants are challenging TADA's very constitutionality. A case is now pending before the Supreme Court of Texas (*Kelly v. Houston Methodist*, No. 19-0390). It is unclear whether TADA will survive legislative and judicial attacks. But what is the right replacement? Policymakers are looking for a dispute resolution mechanism that acts quickly, yet still affords procedural due process.

My Fulbright Research Project

For over a decade, I have closely followed the resolution of medical futility disputes in Canada. For example, in 2008, I was invited to lead a series of presentations and discussions in Winnipeg during the *Samuel Golubchuk* case. Since then, I have consulted with lawyers involved in other

cases, including the *Hassan Rasoui* case as it headed to the Supreme Court of Canada. I have also regularly consulted with Canadian clinicians on projects such as the widely influential, international *Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units.*

Canada has a model dispute resolution mechanism for the United States to follow: the Ontario Consent & Capacity Board. While the CCB was originally designed to handle other forms of cases, it has adjudicated dozens of medical futility disputes. There is no comparable tribunal in any United States jurisdiction. Over the past ten years, in both published articles and major presentations, I defend the CCB as a model dispute resolution mechanism for medical futility conflicts. I also recommend the CCB in articles in *Toronto Life, Toronto Star,* and *Toronto Sun.* More recently, the Supreme Court of Canada has also endorsed the CCB. Still, commentators continue to debate the competence and effectiveness of the CCB for medical futility disputes.

While I can read CCB decisions, that does not adequately illuminate how the CCB really works. To sufficiently understand the advantages and limitations of the CCB, I plan to:

- Participate in CCB hearings and decisions, ideally as an appointed public member
- Interview: counsel for parties, clinician parties, patient and family parties, and CCB members
- Interview critical care physicians and hospital ethicists regarding CCB advantages and limitations

Brain Death

Background

The determination of death by neurological criteria - "brain death" - has long been legally stablished as death in all U.S. jurisdictions. Moreover, the consequences of determining brain death have been clear. Except for organ donation and in a few rare and narrow cases (such as pregnancy in some states), clinicians withdraw physiological support shortly after determining brain death. Until recently, there has been almost zero action in U.S. legislatures, courts, or agencies either to eliminate or to change the legal status of brain death. Despite ongoing academic debates, the law concerning brain death has remained stable for decades.

However, since the Jahi McMath case in 2013, this legal certainty has been increasingly challenged. The persistent salience of this case has spurred other families to challenge clinicians as well. Many of these cases have been litigated in the spotlight of judicial and media scrutiny, further exposing long-standing yet little-known fractures in brain death's biological and conceptual foundations. Admittedly, some families have always had concerns with brain death, whether emotional, biological, or psychological. What has changed over the past five years is that more families have been emboldened to translate their concerns into legal claims challenging traditional brain death rules. While novel, these claims are not frivolous. Therefore, it is important to understand these claims so that we can address them most effectively.

My Fulbright Research Project

As in the United States, brain death is also under attack in Canada. Already, four cases have reached Ontario courts and tribunals. One case, still pending before the Court of Appeal (and probably heading to the Supreme Court), contends that clinicians must accommodate the patient's religious objections to brain death (*McKitty v. Hayani,* No. C65690). We are grappling the same issues in U.S. courts and legislatures. As with MAID and medical futility, comparative legal, ethical, and policy analysis will highlight pathways for both countries.

Dissemination Plan & Timeline

The primary purpose of this project is to compare how Canada and the United States address three pressing health policy issues: (1) medical aid in dying, (2) brain death, and (3) medical futility. Following my demonstrated past practice, I will disseminate my findings as follows.

Publications

- At least two (2) articles in high impact medical journals like *JAMA* that have an international readership
- At least two (2) articles in high impact bioethics journals like *Journal of Medical Ethics* that have an international readership
- At least one traditional law journal publication
- Multiple entries on my own blog, *Medical Futility Blog* that has millions of page-views

Conferences

- Fourth International Conference on End of Life Law, Ethics and Policy (summer 2021 in Salt Lake City, Utah). Note that ICEL2 was in Halifax and that ICEL has a strong participation among Canadian clinician and lawyers.
- American Society of Bioethics & Humanities (ASBH) (Indianapolis, October 2021), this is the largest bioethics association in the world.
- Fifth Annual Conference of the Canadian Association of MAID Assessors and Providers (CAMAP) in 2021
- Second Annual National Clinicians Conference on Medical Aid in Dying (NCCMAID) in 2021
- I am regularly invited to large, high impact conference on these topics.
- I expect to actively participate in university and professional educational events during the term of the visit.

I will write several manuscripts while in Ottawa. I will complete some and will continue editing others after I return to the United States. I will submit most manuscripts by September 2021 and expect that most will be published within the 2021 calendar year or in early 2022.