



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO

# UNDERSTANDING THE RELATIONSHIP BETWEEN SUFFERING AND CAPACITY AT THE END-OF-LIFE: A PILOT STUDY

**Improving the Last Stages of Life**  
**December 2016**

Commissioned by the Law Commission of Ontario

Prepared By

<b>Rosario G. Cartagena</b>	Associate, Fasken Martineau DuMoulin LLP, Adjunct Lecturer, Institute for Health Policy and Management, University of Toronto
<b>Alison K. Thompson</b>	Associate Professor, Leslie Dan Faculty of Pharmacy, Dalla Lana Faculty of Public Health & Joint Centre for Bioethics, University of Toronto
<b>Kaveh Katebian</b>	Partner, Beaconsfield Group
<b>Trudo Lemmens</b>	Professor and Scholl Chair in Health Law and Policy, Faculty of Law, Dalla Lana School of Public Health, and Joint Centre for Bioethics, University of Toronto
<b>Rose Geist</b>	Psychiatrist, Hospital for Sick Children, Trillium Health Partners
<b>Harvey Schipper</b>	Professor of Medicine, Adjunct Professor of Law, University of Toronto
<b>Sandy Buchman</b>	Associate Professor, Department of Family & Community Medicine, University of Toronto, Education Lead and Family Physician practicing in Palliative Care, The Temmy Latner Centre for Palliative Care
<b>Heesoo Kim</b>	Second year law student, Faculty of Law, University of Toronto
<b>Mark Handelman</b>	Counsel, Whaley Estate Litigation Partners

The LCO commissioned this paper to provide background research for its “Improving the Last Stages of Life” project. The views expressed in this paper do not necessarily reflect the views of the LCO.

## ACKNOWLEDGEMENTS

The production of this Paper was a major undertaking in a fairly limited period of time. The authors must acknowledge and thank a number of individuals who contributed to the success of the Paper and were either key advisors for purposes of legal accuracy, assisted to conduct the initial legal and clinical research required or were helpful in conducting the health care provider interviews. These individuals include:

- Sophie MacRae, 3rd year law student at Osgoode Law School and Summer Student, Fasken Martineau DuMoulin LLP
- Gilbert Sharpe, LLB, LLM
- Wendy Lawrence, Director, Compliance, The Hospital for Sick Children
- Michelle DiRisio, PhD Candidate, Leslie Dan Faculty of Pharmacy, University of Toronto
- Rodolfo Gomez, Associate, Beaconsfield
- Min Lee, Executive Assistant, Beaconsfield

We would also like to thank the health care providers who took time out of their very busy schedules to participate in the interview sessions. Their contribution was invaluable.

Finally, we would like to thank our family and places of employment for providing us with windows of opportunity to conduct the interviews, draft our assigned portions of the paper and allow us to finalize the Paper in a short and highly intense period of time.

## EXECUTIVE SUMMARY

This qualitative study and discussion paper focuses on the relationship between suffering and capacity for patients at the end of their lives. We conducted interviews with 14 health care providers in Ontario who have expertise treating patients at the end-of-life. Our initial findings are categorized into three areas: (a) provider perspectives on the relationship between suffering and capacity; (b) suffering is beyond the patient; and (c) disparities between the end of life care context and the legal notion of capacity.

In Part I we provide an introduction to the concept and set out our purpose and methodology. We also summarize key findings and make recommendations for addressing the issues that were identified as part of the qualitative interviews that were conducted.

Part II explores the literature review on the issues of end-of-life, suffering and capacity.

And lastly Part III provides readers with an analysis and discussion from the findings.

Appendix 'A' sets out our methodology and Appendix 'B' is a much more detailed synthesis of the transcript results.

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## I. INTRODUCTION

### A. Overview

In Canada, most individuals experiencing suffering at the end of their lives due to a terminal illness or debilitating disease will one day face difficult choices about how their lives will end. Individuals or their substitute decision makers may have to choose between palliative care and other end-of-life options. Other end-of-life options may include allowing the natural progression of life and death without pain management, withholding or withdrawing life sustaining treatment, and actively choosing to end life with the help of others. The latter is now legally allowed under the circumstances identified in the *Criminal Code*, as amended by *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*.<sup>1</sup>

In these situations, where an individual or their substitute decision-maker chooses to live out their suffering until the end of life, withdraw or withhold life sustaining treatment, or engage others to actively end their life, the relationship between individuals, family, caregivers and health care providers (a group that may include physicians, nurses, and social workers among others) is fluid, transitional and complex.

Individuals face the daunting task of conveying challenging subjective physical and emotional experiences to health care providers who are expected to assess the situation objectively and recommend therapeutic actions based on the best available clinical evidence. An individual's ability to assess their situation and the implications of various treatment options and to make a well-informed decision in these circumstances can, however, be compromised by the context in which the decision is made. For example, emotional, disease-related, familial, possibly even financial, and other contextual factors may interfere with a person's decision. These factors may play a particularly significant role in the context of end-of-life situations.

In this context, health care providers can find it difficult to determine whether patients have the capacity to consent to end-of-life care using a framework such as the *Health Care Consent Act in Ontario*.<sup>2</sup> Health care providers assessing capacity have the burden of determining whether the individual is able to understand the information relevant for making the healthcare decision, and to appreciate the consequences of a decision or lack thereof.<sup>3</sup> Health care providers therefore must distinguish between decisions that are poorly informed (and therefore the person could still be capable if adequate information is provided) and those that are the product of decision-making that has been impaired in some way.

The legal test for capacity in Ontario does not reflect how the individual makes decisions, nor does it clearly reflect an obligation for the healthcare provider to understand the context in which a person makes a decision, and how certain checks and balances may be helpful, such as: discussions with close family or friends or a requirement that capacity must be assessed over a period of time.

Consequently, a tension exists between this legal capacity framework, the bedside care of patients at the end of their lives who are conveying their suffering to healthcare team members and the ability to translate the patient's suffering into end-of-life care.

The tension has been further augmented by the recent Supreme Court of Canada ("SCC") decision, *Carter v. Canada (Attorney General)*<sup>4</sup> [hereinafter, "**Carter**"] wherein the SCC provided some general parameters that have to be followed in legislation that sets out the circumstances in which medical-assistance in dying ("**MAID**") should be accessible to individuals.

The SCC specifically considered the application of the law for cases that involve a competent adult person who:<sup>5</sup>

- clearly consents to the termination of life; and
- has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.

The SCC thus appears to have implied that consent and intolerable suffering are separate and distinct factors that can be evaluated independently of one another at the bedside.

In responding to the *Carter* decision, the federal government amended the *Criminal Code*, also including separate requirements concerning capacity and intolerable suffering. Physicians and nurse practitioners are charged with assessing capacity in the context of MAID, while intolerable suffering is framed as a subjective issue to be considered from the patient's perspective. Both are included in the legislative eligibility criteria, which require that an individual:<sup>6</sup>

- be eligible for health services funded by the government, or but for an applicable minimum period of residence would be eligible;
- be over the age of 18 and capable;
- have a *grievous and irremediable medical condition*; and,
- be making the request voluntarily, having given consent after having been informed of other means available to relieve their suffering, including

palliative care.

Suffering is provided for in the definition of grievous and irremediable, which sets out that an individual has such a condition when he or she: <sup>7</sup>

- has a serious and incurable illness, disease or disability;
- is in an advanced state of irreversible decline in capability;
- has an illness, disease or disability causing physical or psychological suffering that is intolerable to him or her and that cannot be relieved under conditions that he or she considers acceptable; and,
- is at a point where his or her natural death has become reasonably foreseeable, taking into account all medical circumstances, without a prognosis necessarily having been made as to the specific length of time he or she has remaining.

As a result of the *Carter* decision and subsequent legislative amendments, and the lack of research available on suffering, capacity and end-of-life generally, we sought to determine if there was an intrinsic relationship between suffering, including intolerable suffering, and decision-making capacity to make end of life treatment choices, including and beyond MAID. In order to do so, we undertook a mixed-methods study involving literature review and the analysis of new qualitative data collected through interviews with health care providers in Ontario.

## **B. Purpose and Scope**

### **1. Purpose**

Our primary objectives were to assess how suffering, including intolerable suffering, is understood by members of the decision-making triad of healthcare providers, patients, and family, and to clarify the relationship between suffering and a patient's capacity to consent to end-of-life treatments.

Our purpose for exploring this topic is primarily to:

- shed light on how healthcare professionals assess suffering and capacity to consent to end-of-life treatment within the context of the patient-family-professional decision-making triad; and
- enhance the translation between the legal regulatory framework language and the language used by a healthcare provider at the bedside of a patient experiencing suffering in the last stages of life.



The authors ultimately intend for this research to assist the healthcare community to better understand how suffering can impact decision-making capacity at the end-of-life and if there is found to be a correlation, whether this needs to be addressed in some meaningful way or whether from a policy perspective, it should have no influence on the way in which care is delivered. The data gathered from this research will also assist the Law Commission of Ontario (“LCO”) in executing their projects and reports.

It is important to note that for the purposes of this research paper we have utilized the term “MAID” for instances in which health care providers actively engage in ending a patient’s life at the patient’s request. We have not used the term “physician-assisted death” as used by the SCC in *Carter*, or any other such term, as the term MAID is currently in force pursuant to the *Criminal Code*.

## **2. Scope**

### In Scope

Our study is from the point of view of the health care professional. Although we have employed extensive literature review to supplement the qualitative research findings for healthcare professionals and thus, reviewed literature specifically focused on the family, there is a gap in this portion of the study. Nonetheless, we submit that the findings from this research will assist to provide the first step towards enhancing the translation of patients’ goals in end of life care to healthcare providers.

Finally, our research project focuses on end-of-life care generally and is not specific to MAID. End-of-life care also includes palliative care and the withholding or withdrawing life sustaining treatment. Life sustaining treatment refers to artificial ventilation or nutrition keeping the individual alive. In Ontario, patients may consent to the withdrawal and withholding of life sustaining treatment. MAID is one of the available options for individuals receiving end-of-life care.

### Out of Scope

As mentioned above, out of scope for this study are qualitative interviews focused on the patient as well as family or friends of the patient suffering at the end of their life and the way in which they perceive the impact of suffering on their capacity or lack of capacity to make health care decisions.

### C. Key Findings and Recommendations

As discussed in the paper, this project is a “pilot study.” It is a preliminary exploration of the relationship between capacity and suffering at the end-of-life. On the basis of our initial discussions and the literature review we put forward that while capacity is a legal concept that is approached cognitively in Ontario, suffering is a highly subjective, emotional, and personal experience that is difficult to quantify, measure, or even verbalize. By conducting qualitative interviews with health care providers we sought to determine if there was a relationship between the suffering people experience at the end of their lives and their capacity to consent to treatment.

Our study found that because decisions made at the end of life are highly consequential and made in a context in which intense emotions and a variety of factors interact with decision-making, existing mechanisms for capacity assessment may be inadequate or insufficient for this particular patient group in the circumstances of their condition. By merely relying on a legal cognitive capacity test, health care providers are unable to account for the entire intricate web encircling a patient at the end of their life. They also find it hard to assess how suffering can affect a patient’s decision-making ability.

At this initial stage of our research, it appears that capacity assessments as they are currently conceived and conducted are not sufficiently capturing the complexity of decision making at the end-of-life. This suggests that either capacity assessments have to be refined, or there is a need for an additional mechanism. There was resounding agreement between health care providers that emotional, social, family and relational issues contribute to both the degree of suffering and the decision-making, particularly at the end of life. In fact, we learned that factors that contribute to a loss of the integrity of the self, a sense of being unable to cope and a profound experience of weakness, all contribute to suffering of the individual. The capacity test employed in Ontario does not, so it seems, sufficiently capture this complexity. We are missing a tool for assessing how all of these other factors can influence a patient’s suffering, such that health care providers can fully assess how a patient’s decision to make healthcare decisions is influenced by factors that could otherwise be addressed. There was at this point no clear agreement about how this would have to be addressed, whether it is as part of a more complex capacity assessment or through a different tool. There was agreement that we need to somehow capture the emotional agony felt by patients when they are suffering and its impact on their ability to make decisions, and potentially offer avenues for people to cope with suffering before making specific decisions at the end of life.

Based on our findings we recommend that a task force be created to further explore this issue and if warranted, develop guidelines or a tool to assist health care providers in supporting

patients who are in agony, at the end of their lives and who are faced with difficult decisions in highly complex circumstances. We also recommend exploring the possibility of specialized training for health care providers to promote their awareness when they are performing capacity assessments in the context of end-of-life. Another option worth exploring is whether we should create specialized roles, such as ‘Capacity Assessors’ and even interdisciplinary ‘Capacity Teams’ so that individuals who are at the end-of-life are accurately assessed. Our respondents told us that the current legal test for capacity is insufficient when they are interacting with a patient that is suffering. The participants themselves are also often so distraught by the suffering of the patients, as well as by the family dynamics, that it is very challenging to conduct an accurate capacity assessment. Our Canadian society is transforming and healthcare is continually evolving to address new legal challenges and issues. We hope that these initial findings will encourage lawmakers and policymakers to turn their minds to this issue and take the appropriate measures for patients suffering at the end of their lives.

As it relates to MAID, because capacity assessments are part of the legal test required when ending a patient’s life and this is territory for which there is not widespread experience, it is extremely important that we immediately ensure that we have the means and processes to collect very rich robust data about our early experience. Only in that way will we be able to evolve MAID in such a way that it will be applied consistently and reflect the clinical realities and needs of patients.

## **II. REVIEW OF THE LITERATURE ON END-OF-LIFE, SUFFERING AND CAPACITY**

### **A. Overview**

This section provides a summary of academic scholarship, government publications, legislation and case law as an overview of the major concepts grounding this study: end-of-life, suffering and capacity. The purpose is to provide the context necessary to understand the findings and discussion. The full methodology for this literature review can be found in Appendix A.

To set the context for this section, we first review understandings and applications of end-of-life. We then provide a summary of how suffering is defined, as well as highlight our finding that the relationship between suffering and capacity in peer-reviewed publications is lacking. We then conclude by setting out the legislation, case law and gaps as it relates to the interpretation of capacity in Ontario, and generally. The idea is to provide the context for the qualitative study which will explore the relationship between end-of-life, suffering and capacity at the patient bedside.

## B. End-of-Life

To situate the framework for our qualitative research on the relationship between suffering and capacity, it is important to set out what is meant by the term “end-of-life.” There is no single definition adopted by organizations, health care providers, government bodies or commentators working in and studying the end-of-life, and, as demonstrated by the qualitative findings, individual experiences are subjective. This literature review considers interpretations of the end-of-life from a variety of academic, legal and clinical perspectives.

The term end-of-life is used largely, though not exclusively, in the context of end-of-life care. Care at the end-of-life is intended to and does provide relief from suffering. However, while “dying is part of living”, care is neither certain or uniform, and therefore the end-of-life period is not exclusive to discussions of care.<sup>8</sup> The diversity of definitions is reflective of heterogeneity in experiences of the end-of-life itself. *The Declaration of Partnership and Commitment to Action on Advancing High Quality, High Value Palliative Care in Ontario* (“**Declaration of Partnership**”), which uses “end-of-life” in reference to the time in the course of a chronic disease where death is likely imminent, identifies that access to palliative and end-of-life care is not consistent across Ontario.<sup>9</sup> Provincially, nationally and internationally, differences in geography, culture, age, disease trajectory and medical technology impact patients, families, medical practitioners and society as a whole in the context of the end-of-life.

At the outset, there is an overlap between end-of-life and palliative care in the literature. While some use the terms synonymously, others differentiate between them. The World Health Organization (“**WHO**”) uses the term “end-of-life” and has published widely in the area of palliative care, but does not define end-of-life explicitly. The WHO has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems.”<sup>10</sup> The Declaration of Partnership includes a government and community endorsed definition which, similar to the WHO definition, provides that palliative care “aims to relieve suffering and improve the quality of living and dying.”<sup>11</sup>

End-of-life is described as a later stage within the more broadly defined period encompassed by palliative care. The Declaration of Partnership, for example, states that palliative care “*includes end-of-life care*, but is not limited to the time immediately preceding death” (emphasis added).<sup>12</sup> *The Global Atlas of Palliative Care at the End of Life*, published by the World Palliative Care Alliance and the WHO, differentiates between “palliative care in the years before death” and “end-of-life palliative care.”<sup>13</sup> The Declaration of Partnership and the WHO both state that

palliative care is part of a continuum of care from diagnosis through to the end of a disease.<sup>14</sup> The Canadian Medical Association has also addressed the difference between end-of-life and palliative care, explaining that palliative care involves a longer period of time and broader focus that begins upstream, when a person first becomes ill with a life-threatening illness.<sup>15</sup> The experience of suffering and its impact on decision making capacity, therefore, may change throughout the course of palliative care as the end-of-life phase approaches.

It is relevant to acknowledge that there is also literature defining end-of-life care as broader than palliative care because of palliative care's traditional associations with specific diseases. The British Columbia Ministry of Health, explains that palliative care has "often been associated with a limited number of diseases, primarily cancer" and therefore "the use of 'end-of-life care' means an intention to offer specialized, holistic services to the wider group of people approaching death."<sup>16</sup> The Ontario Medical Association ("OMA") also emphasizes that end-of-life care means assistance for those at the end of their life regardless of medical diagnosis, health condition or age.<sup>17</sup> The WHO, however, does include a broad variety of conditions when discussing palliative care, including cancer, cardiovascular disease, respiratory diseases, HIV/AIDS, diabetes, multiple sclerosis and Parkinson's disease. The Declaration of Partnership reiterates that palliative care is "not limited to cancer diagnoses."<sup>18</sup>

The beginning of the end-of-life period and the time frame it includes can vary based on individual experiences. Some diseases progress relatively predictably towards the end of life, while other causes of death are sudden and unexpected. The Royal Society of Canada explains that the path from diagnosis to treatment, and finally, death, can include many transitions.<sup>19</sup> The Canadian Institute for Health Information defines end-of-life care to include care for "people in decline who are deemed to be terminal or dying in the foreseeable (near) future".<sup>20</sup> The Declaration of Partnership sets the intention to "treat the episode of care as starting from the point of entry to the system through death and post-death bereavement."<sup>21</sup> Including bereavement extends the end-of-life period past death into the stage of grief, recognizing the impact on family and friends. The OMA, using end-of-life and palliative care synonymously, defines end-of-life care to include assistance for persons who are facing imminent or distant death.<sup>22</sup> As diseases can progress differently among patients, the transition to a stage that is considered the end-of-life can be difficult to identify precisely. One group of researchers observes that end-of-life care must "serve those who become increasingly frail, even without a life threatening illness."<sup>23</sup> Cancer Care Ontario uses two weeks before death when studying emergency department use at the end-of-life, while other research studying care in the palliative period focuses on the final six months in measuring similar trends.<sup>24</sup> The Canadian Researchers at the End-of-Life Network narrow end-of-life generally to the last few days of life or weeks when a person is irreversibly dying.<sup>25</sup> The narrower definitions are an example of defining end-of-life as

a specific subset period of palliative care. Before and during the variable period of end-of-life, suffering and capacity may shift.

Both end-of-life care and palliative care are discussed largely in the context of longer-term illness, as opposed to unexpected death. The Declaration of Commitment specifically looks at illness and advanced chronic disease.<sup>26</sup> The British Columbia Ministry of Health explicitly states that the term end-of-life care has generally been adopted to refer to services provided for persons “dying from any cause, *other than a completely sudden and unexpected one*” (emphasis added).<sup>27</sup>

The scope of our study is on terminal illness and debilitating disease. The trajectory of the last phase of life, the experience of suffering and the capacity to make decisions can vary depending on medical condition, treatment plan, and other individual factors. The amendments to the Criminal Code introduced by *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* do not define end-of-life, but do include in the Preamble that the Government of Canada supports the development of a “full range of options for end-of-life care”, implying that medical aid in dying is part of such a range.<sup>28</sup> This adds to care options available at the end-of-life to address suffering and, unlike an unexpected death, means dying can be specifically contemplated and medically induced.

Experiences at the end-of-life can vary depending on the culture and geography. Robert Blank, professor at the University of Canterbury in New Zealand, observes that perceptions of end-of-life and associated care may depend on factors such as the life expectancy in an area, religion, access to treatment, and whether illness and end-of-life are viewed as individual or collective/familial experiences.<sup>29</sup> The societal perception of end-of-life may be shaped by the leading causes of death in that society. The use of medical technology can also influence the experience of end-of-life, as some cultures rely heavily on interventions such as artificial feeding, while others do not.<sup>30</sup> Blank, notes that the likelihood of a person dying in hospital is also determined by geography, with the highest rates of in-hospital deaths being recorded in the United Kingdom and United States. This latter trend, Blank observes, reflects weak family care structures and a high prevalence of life-support technology.<sup>31</sup> Despite Blank’s observations, the Declaration of Partnership notes, based on the Ontario context, that most individuals prefer to die at home or as close to home as possible.<sup>32</sup> These variables may have an impact on the physical and emotional experience of the end-of-life.

The approach to dying, whether to sustain life as long as possible or to see dying as part of an ongoing process, adds complexity the task of defining end-of-life. For instance, researchers at Pramukhswami Medical College in India observe that in Hindu philosophy, people detach themselves from material concerns and prepare for death spiritually through prayer, scripture

and meditation.<sup>33</sup> In Ontario, discussions with Indigenous leaders summarized in the *Palliative and End-of-Life Care Provincial Roundtable Report* highlight that “when providing end-of-life care to Indigenous people, appropriate space is required for traditional practices such as smudging, cedar baths or other ceremonies.”<sup>34</sup> Openness to discussing death and the involvement of family and community members in decision-making varies across cultures and impacts end-of-life treatment.<sup>35</sup> The Declaration of Partnership identifies several communities that have been marginalized in the provision of end-of-life care, including First Nations, children, and individuals living with disabilities.<sup>36</sup> A lack of appropriate care can limit the options that an individual has to address suffering.

As conveyed by this review, there is no single definition or experience, from the perspective of researchers, physicians, patients or society of the end-of-life. This highlights the complexity of providing end-of-life care, making end-of-life decisions, experiencing suffering, and developing a legal regulatory framework that offers a range of end-of-life care options in light of the legal test for capacity to consent to treatment and the criteria for access to MAID that have been identified in the new legislation. It is important to acknowledge that the Declaration of Partnership is a commitment to provide better care at the end-of-life, and that the 2016 Ontario Budget allocates \$75 million over three years towards this initiative in order to create greater access to end-of-life care in Ontario.<sup>37</sup>

### **C. Suffering**

Unlike the term “end of life,” the term “suffering” is subjective by its very nature. This fact is well-understood by the SCC who made clear in *Carter* that the criteria required to qualify for physician assisted death is that the individual find themselves with enduring suffering brought on by a grievous or irremediable medical condition that is intolerable to the individual in the circumstances of his or her condition. In this section, we present a framework informed by a review of academic literature that is useful in conceptualizing what it means to suffer, or to find oneself in a situation that causes intolerable suffering. The most common definition of suffering cited by research papers examining the wish to hasten death was proposed by Cassell<sup>38</sup> who defines it as a specific state of severe distress related to the imminent, perceived, or actual threat to the integrity or existential continuity of the person.”

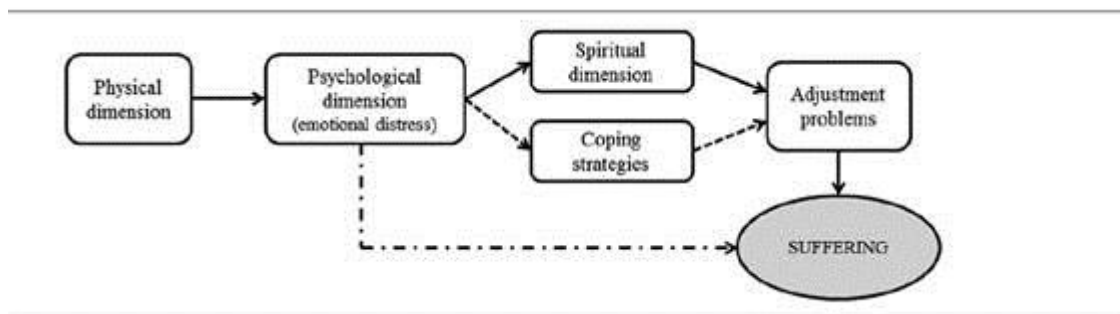
According to Cassell, suffering is a “multidimensional and dynamic experience of severe stress that occurs when...the regulatory processes, which would normally result in adaptation, are insufficient, leading to exhaustion.”

He proposes conceptualizing suffering, or the intolerability of a medical condition, through three dimensions:

1. physical (pain, physical distress and loss of autonomy);
2. psychological (emotional distress); and
3. spiritual.

A diagrammatic representation of Cassell's model is presented below.

Cassell is not the only scholar to conceptualize suffering in physical, spiritual and social terms. Krikorian *et al.*<sup>39</sup> propose a framework illustrated in figure 1 that suggests physical, psychological and spiritual dimensions which can be magnified in the absence of coping strategies and worsened in the presence of adjustment problems.



To help in identifying whether suffering is present, some researchers have worked to develop assessment tools that can be used at the bedside.

The State-of-Suffering-V (SOS-V) survey was developed by Ruijs *et al.*<sup>40</sup> to assess the presence of suffering and has been used in studies of cancer patients at end of life. Their tool measures the tolerability of the patient's medical condition by examining 69 aspects of suffering across five domains:

- Medical signs and symptoms;
- Loss of function;
- Personal aspects,
- Aspects of environment; and
- Nature and prognosis of the disease.

The SOS-V was first validated in a study of 64 terminally-ill cancer patients in the Netherlands who were assessed to have less than four months to live. SOS-V was shown to be highly



correlated with a previously established suffering survey while providing more information on the psychosocial aspects of suffering.<sup>41</sup>

In another study of 60 terminally ill cancer patients in the Netherlands expected to die in less than six months, the SOS-V found:<sup>42</sup>

- The most unbearable symptom was weakness, reported by 75% of patients, while pain was unbearable in just 25%;
- When symptom intensity was high, pain, loss of control over one's life and fear of future suffering were unbearable in 89-92% of patients;
- When symptoms intensity was low, loss of control over one's life, vomiting and not being able to do important things frequently were unbearable in 52-80% of patients; and
- Physical suffering, loss of meaning, loss of autonomy, experiencing to be a burden, fear of future suffering, and worrying more frequently occurred in people suffering unbearably overall.

Moreover, the psychosocial domains of suffering were highly correlated with the decision to hasten death in studies that examined end-of-life treatment decisions of terminally-ill patients.

In a study of 72 terminally-ill cancer patients in Australia, Kelley et al.<sup>43</sup> found that five factors made important contributions to end-of-life decisions:

- Concern with physical symptoms, especially pain;
- Psychological distress, when patient perceives themselves to be a burden to others;
- Religious or moral beliefs;
- Lack of emotional support from doctors, defined as inadequate display of care, availability and concern; and
- Demoralization, resignation of the inevitability of death, frustration at the loss of independence and freedom.

The authors concluded that psychosocial factors are central to a patient's decision-making process regarding the choice to hasten death. They conclude "existential suffering" underlies requests for assisted suicide and is defined by:

- Fear of losing autonomy;
- Fear of losing dignity;
- Guilt (religious or otherwise);
- Poor relations with others (family and friends); and
- Lack of physician empathy and communication.

Examining “wish-to-die” requests of 30 terminally ill cancer patients across multiple provider institutions in Basel, Switzerland, Ohnsorge *et al.*<sup>44</sup> concluded that the wish to hasten death is motivated by physical as well as psychological and social factors and that physicians can clinically treat these patients if they worked to understand their motivations, feelings and thoughts.

This finding was corroborated by a 2004 study of 56 patients referred to an Australian hospice unit by Kelly *et al.*<sup>45</sup> who found that among the 14% of patients having a high wish to hasten death, 80% had a psychiatric diagnosis. In comparison, only 21% of patients with no wish to hasten death had a psychiatric diagnosis. Furthermore, the researchers found 50% of their patients had current major depressive episode, of which 83% had a high wish to hasten death, leading them to conclude that management of psychological concerns is central to caring for patients at end-of-life.

In a study of 15 terminally ill cancer patients in Thailand, Nilmanat *et al.*<sup>46</sup> found a strong relationship between the social dimensions of suffering and a wish to hasten death, and that this wish diminished once social issues were managed. They concluded, after in-depth interviews, that “the desire to hasten death triggered by uncontrollable pain and/or distress symptoms, intensified by overwhelming feeling of worthlessness and a sense of being a burden to others... however, when symptoms are well-managed and patients feel in control, the wish for death disappeared.”

This section has provided a brief overview of the highly subjective experience of individuals who are suffering. The section that follows discusses the much more objective notion of capacity.

#### **D. Capacity at End-of-life Briefly Explored: An Ontario Lens**

“Capacity” to make a treatment decision is fundamental to the process of giving informed consent to treatment. Informed consent is the ethical and legal cornerstone to respecting a patient’s autonomy: capable individuals should be allowed to make their own treatment decisions. Ontario law requires health care providers, except in cases of emergency treatment, to obtain informed consent to treatment, from the patient if he or she is capable, and from the substitute decision-maker if the patient is incapable.<sup>47</sup> The Law Commission of Ontario emphasizes that the question at hand is whether it is just for an individual to face adverse consequences which she or he was not able to understand or foresee.<sup>48</sup>

## **1. Legislation Defined**

In Ontario, “capacity” in the context of a patient’s health-related decision making is defined by the *Health Care Consent Act, 1996* (“**HCCA**”). The HCCA defines capacity through a two-part test:

A patient must be “able to understand the information relevant to making a decision about the treatment,” and; a patient must be “able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.”<sup>49</sup>

“Ability to understand” refers to objective criteria: is the person able to receive, retain and process the relevant information sufficiently to make a decision?

“Ability to appreciate” refers to the subjective ability to apply that information to one’s own condition: is the patient able to comprehend how the decision will impact his or her own condition?

As stated in the LCO Interim Paper,<sup>50</sup>

While the test focuses on the ability to understand and appreciate the relevant information as opposed to actual understanding and appreciation, there are concerns that in practice this distinction may tend to blur. Similarly, there is a risk of the “appreciation” branch of the test collapsing into an outcomes-based approach, as in practice it may be difficult to distinguish between an inability to appreciate the consequences of a decision from an assessment of the nature and level of risk that differs from that of the person carrying out the assessment. As well, while legal capacity as it is understood in Ontario may fluctuate, so that a person who has legal capacity at one time may not have it at another, because determinations of incapacity may have long-term consequences (as with guardianship, for example), it may be difficult to ensure that substitute decision-making arrangements are only in place where they are truly necessary.

The Law Commission also emphasizes the following key elements of the capacity framework in Ontario:<sup>51</sup>

1. Presumption of capacity: Individuals are presumed capable to make their own decisions, and others are entitled to rely on that presumption unless there are reasonable grounds for believing otherwise.
2. Cognitive and decision-specific approach to capacity: The test for capacity to make a particular decision is not whether the individual will make a wise decision, or whether the individual has a particular disability that may affect

memory, understanding or reasoning, but whether the individual has the ability to “understand and appreciate” the relevant information. As is discussed at more length in Part Two, Chapter I.B, it is not necessary for the individual to actually understand and appreciate the information, but only that they have the ability to do so. Further, capacity is understood not as a global quality, but as particular to specific types of decisions: an individual may have capacity for some types of decisions and not others. He or she may also have capacity at some times and not others.

Therefore as stated above, the HCCA takes a “cognitive- functional” approach to defining capacity. That is to say, unless patients are proven to be incapable of understanding and reasoning through a treatment decision, and appreciating the consequences of their decision, they are capable of consenting to treatment. Ultimately, consent has to be informed, voluntary, and not be obtained through misrepresentation or fraud. In the HCCA, these issues are treated as potential challenges to informed consent, but the line between informed consent challenges and challenges to capacity is thin.

## **2. A Brief Overview of Capacity Case Law**

This transformation under the HCCA is perhaps best illustrated by the Supreme Court of Canada’s decision in *Starson v. Swayze*.<sup>52</sup> The case originated at the Consent and Capacity Board, which upheld the finding by Dr. Swayze that Professor Starson was incapable of giving or refusing consent to treatment of his mental condition. Professor Starson appealed, eventually to the Supreme Court, which reversed the Board’s Decision, holding the evidence did not establish, on a balance of probabilities, that he was incapable.

Starson, an intelligent man suffering from bi-polar disorder, was found incapable of consenting to psychiatric treatment by a treating physician and appealed this finding to the Consent and Capacity Board who affirmed the physician’s position and found Starson failed to acknowledge his illness while holding he could not understand the consequences of refusing consent to medication.

Starson knew that his brain did not function normally, but did not view this condition as an illness and refused to consent to medication because he preferred the untreated mental state. The Superior Court of Justice held that the Board’s decision was not reasonable, and the Ontario Court of Appeal and SCC agreed, stating the ability to understand information that is relevant to making a treatment decision requires the “cognitive ability to process, retain and understand the relevant information”<sup>53</sup> and appreciation of foreseeable consequences requires being able to apply the relevant information to the person’s circumstances in order to weigh the risks and benefits.

This strict cognitive function requirement, found in the HCCA has been confirmed in several other cases, including *Bartoszek v Ontario*<sup>54</sup> in which the Ontario Superior Court ruled the test for capacity is not whether patients fail to appreciate the reasonably foreseeable consequences, but whether they are cognitively able to do so, and *Neto v Klukack*<sup>55</sup>, in which the Ontario Superior Court reaffirmed its position in *Bartoszek* that “it is mental capacity, not wisdom that is at issue.”<sup>56</sup> All these judgments make the point that the lack of understanding and/or appreciation must be due to an inability to understand or appreciate and not some other reason.

The prevailing issue at the time the HCCA was drafted was not end-of-life decisions, however and therefore the application of consent to treatment in such end-of-life situations has not been fully explored. Below is a further discussion of gaps that have been identified in the current capacity test.

### **3. Gaps in the Capacity Test**

In order to better understand the relationship between suffering and a patient’s capacity to consent to end-of-life treatments, it is important to evaluate whether a patient’s capacity can be determined correctly and reliably. Capacity assessments are an increasingly essential tool in medical decision-making contexts due to the aging population, the political and social climate and growing emphasis on patient autonomy.<sup>57,58</sup> Unfortunately, current assessment standards and practices seem to ineffectively account for the complexities fundamental to capacity. The discussion paper published by the LCO on legal capacity show that there may be a substantial gap between the statutory concept of legal capacity and the practical understanding and implementation by professionals, families and those directly affected.<sup>59</sup> A survey of Canadian and American physicians revealed that decision-making capacity (“DMC”) evaluations are viewed as more challenging than other types of evaluations with nearly half reporting feeling that the evidence-base for DMC assessments was weaker.<sup>60</sup> A majority of the psychologists surveyed in Oregon also raised concerns over the reliability of competency assessments.<sup>61</sup> As we will discuss further, evidence from Belgium and the Netherlands related to euthanasia involving psychiatric patients illustrates how, in the context of life-ending intervention in other jurisdictions, competency assessments may not always be very rigorous.

Competency assessments are inherently difficult, likely due to the fluctuating nature of capacity<sup>62,63</sup> and the often ignored influence of emotion.<sup>64</sup> The LCO acknowledges the fluctuating levels of capacity as one of the key challenges of capacity assessments.<sup>65</sup> A study by Henwood et al. suggests that capacity to give informed consent can be temporarily affected by a number of factors including confusion, pain and medications.<sup>66</sup> In end-of-life situations, DMC

may be particularly influenced by emotions such as hope, frustration and anger, as well as by moods, passions and values.<sup>67</sup>

Notwithstanding the lack of consensus on how to incorporate these factors into capacity assessments,<sup>68</sup> some have argued that defining competence without accounting for emotions and values is empirically inadequate.<sup>69</sup> The LCO also raises the concern that a strict cognitive approach may fail to sufficiently value other attributes that may impact decisions, such as preferences and emotions.<sup>70</sup> Appraisal, one of the key components of competency, refers to the process of attaching personal meaning to situations. Philosophy professor Louis Charland asserts that satisfying this component requires emotions because individuals must have the capacity to attribute personal significance to their decision and its potential consequences.<sup>71</sup>

Another challenge facing capacity assessments is the pressing lack of professional guidance for health care providers. Training and guidance on capacity assessments are left to the health regulatory colleges and vary considerably.<sup>72</sup> A comprehensive review paper by Lamont et al. suggests that medical education and training tend to neglect ethical, professional and legal responsibilities in relation to treatment consent and knowledge gaps exist across various disciplines.<sup>73</sup> This may explain the problematic lack of consensus on the definition of the term 'capacity'<sup>74</sup> as well as on assessment standards among health professionals.<sup>75,76</sup> The LCO suggests that this lack of clear standards for assessments and the inadequate training or education within some professions create confusion and anxiety around capacity assessments and add to the confusion and complexity of the system.<sup>77</sup>

Evidence suggests that standards of competence are influenced by beliefs and values of the assessing health professional<sup>78,79,80</sup> as well as by their disciplinary, sociocultural, religious and demographic characteristics<sup>81</sup>. This assessor variability is a difficult problem due to the inherent subjectivity of the process; for example, physicians may disagree on whether requesting assisted suicide to reduce burden on others is rational.<sup>82</sup> An analysis of the oral evidence submitted by experts from a wide range of backgrounds in the UK showed evidence of assessor inconsistency in areas including definitions and boundaries of capacity and the impact of factors which may influence capacity such as depressive symptoms, motivation, rationality and the presence and severity of mental disorder.<sup>83</sup> A study by Annabel Price suggests that in the context of end-of-life where patients may suffer from mental health conditions, competency assessment is much more complex and even more likely to vary depending on the physician's commitment to assisted dying.<sup>84</sup> The LCO notes that communication barriers or cultural differences may also affect capacity assessments, especially in linguistically and culturally diverse places such as Ontario.<sup>85</sup> Other factors that may result in erroneous determination of incompetency include: use of jargon and technical terms, hearing impairment, physical impairment, communication breakdown and behavioural problems.<sup>86</sup>

Some psychiatric conditions are known to increase risk of incapacity.<sup>87,88</sup> Patients who request psychiatric assisted dying may often have compromised abilities to cope with adversity.<sup>89</sup> Moreover, concerns specific to psychiatric conditions aggravate the problems facing capacity assessments. Fluctuations in capacity may be amplified due to cognitive fluctuations known to occur in some psychiatric conditions such as dementia and Parkinson's.<sup>90</sup> Proper diagnosis, which should inform those assessing capacity to make treatment decisions, may also be very difficult because many depressive symptoms are similar to physical symptoms associated with a terminal illness.<sup>91</sup>

Problems with competency assessments in the mental health context are illustrated by evidence from Belgium and the Netherlands. For example, a Belgian psychiatrist appeared to apply a low threshold for capacity and deemed 100 consecutive psychiatric patients requesting assisted death to be capable even though many of them were suffering from mental disorders that are often associated with lack of capacity.<sup>92</sup> An in-depth analysis of case summaries of psychiatric MAID in the Netherlands by Scott Kim and colleagues indicated that in some reported cases, no independent psychiatric expert was involved and assisted suicide proceeded even when physicians had unresolved disagreements about the patients' competence.<sup>93</sup> In over half the cases, capacity was presumed even when the patient had disorders known to increase the risk of incapacity.<sup>94</sup> Moreover, the capacity determination in most cases was a simple global judgment of capacity, without much detail available about how challenges to capacity were assessed, even in patients with disorders that increase the risk of incapacity.<sup>95</sup>

Some authors and reports have pointed out that more attention has to be paid to capacity-related challenges in the end of life context. In a recent report, the Canadian Association for Community Living emphasizes, for example, how a variety of contextual factors, including psychological, social and economic factors, may impact on people's capacity and provision of informed consent, and that additional measures may be needed to take into account the vulnerability of patients at the end of life.<sup>96</sup>

For some, a competency assessment model which requires at least two evaluations performed at different times<sup>97</sup> and which assesses fundamental abilities, such as processing information, reasoning and communication, separately and in addition to the abilities specific to a particular decision<sup>98</sup> may better account for the complex and fluctuating nature of competency. The effectiveness of our capacity assessments will influence our understanding of how suffering impacts capacity and thus it is important to keep the empirical shortcomings in mind when pursuing these objectives. The LCO Discussion Paper emphasizes that when the stakes are high, i.e. when a decision has very significant consequences – which in the end of life context is certainly the case when a decision is irreversible – it becomes particularly important to ensure

appropriate access to information and, where needed, to provide support in the processing of all the relevant information.<sup>99</sup> This may require assistance by others such as family members or patient advocates.

In *Carter*, the Supreme Court approvingly referred to the trial judge's statement that capacity assessment is already routinely undertaken in end-of-life situations. The trial judge and the Supreme Court assumed therefore that physicians are well equipped to do the same when it comes to MAID. Yet, the new legislation does not treat active life-ending measures in exactly the same way as other forms of end-of-life care. Unlike in other end-of-life decision-making, a second physician has to be consulted to confirm that all access criteria, including capacity to consent, are fulfilled. In addition, the legislation refers to specific criteria that have to be fulfilled before MAID can be provided. One of the criteria, which was also recognized by the Supreme Court, is the intolerable nature of suffering.

A key question remains therefore why it is that particular requirements are imposed, also with respect to capacity assessment. Is there a reason we should be extra cautious about capacity in this context?

A couple of interrelated points can be raised here. First, it is clear from our review of the literature that challenges to capacity, particularly in complex situations at the end-of-life where several factors may impact capacity, are recognized more generally. So while we already rely on capacity assessment in the end-of-life context, this may be for quite pragmatic reasons, and does not imply that there are no problems with capacity assessment. With the legalization of active requests for life-ending interventions, it can be expected that we will be confronted more frequently with requests for actions that require a capacity assessment. Before the adoption of the legislation, situations at the end-of-life where capacity had to be assessed in the context of controversial decisions that could lead to the immediate termination of life were limited to cases of withdrawal of life-support. We will arguably see an increase in the number of situations where there may be concerns about whether a person's capacity to make decisions with drastic consequences is affected. Concerns about how capacity is being assessed at the end of life are thus becoming more important as more people may be affected. Capacity assessment as a practical tool to screen who can make what decision will be more important.

A second reason is that decisions for MAID have more drastic consequences. The impact of error is greater as the decision is irreversible. In most other end-of-life situations, even in many-if not, most--treatment refusal cases, patient may still change their mind later without inevitable loss of life. The concrete performance of a life-terminating action cannot be changed or undone. If it is the case, as the interview data discussed further suggests, that patients frequently change their mind about whether they would prefer to die, then it becomes more problematic to make drastic decisions on the basis of a form of assessment that may not be



very refined. The fluctuating and complex nature of suffering may be associated with the changes in decision-making or even impact on capacity. It is one thing to work with an easy presumption of capacity to delay the provision of a potential life-saving treatment, if that decision can be reversed later. It is quite another to rely on an imperfect tool when it results in an irreversible end-of-life decision. This makes it more important to ensure that capacity and its relation with suffering in the end-of-life context is well-understood and that capacity assessments are sufficiently refined.

As mentioned earlier, one of the critiques of current competency assessment tests and practices is that they do not sufficiently take into consideration the inherent contributions and role of emotions in decision-making.<sup>100</sup> Emotions are arguably particularly intense in the context of end-of-life, and often associated with and interacting with suffering. Emotional connections to others and even emotional interactions with others in this context may impact decision-making. Could this be even more so when we are dealing with active life-ending actions, where there may be significant disagreement among those involved and affected (i.e. the patient, health care providers, and family and loved ones)?

## **E. The Relationship between Capacity and Suffering**

We sought to understand the relationship between capacity and suffering through a systematic review of peer-reviewed literature. Unfortunately, we were not able to identify any papers published in the past 10 years that examined whether capacity influences suffering, or vice-versa. Consequently, we are left to conclude that the relationship between these two central issues in Canada's physician assisted dying debate has not been studied in depth.

## **F. Conclusion**

This section has provided an overview of legal and scholarly understandings of the concepts forming the basis of our qualitative research. The literature demonstrates that the end-of-life experience varies for each individual, as will the experience of suffering. In order to provide informed consent for end-of-life care, individuals require legal capacity to make a treatment decision. Capacity is clearly defined by legislation in Ontario, but can be time and issue specific for each individual. Peer reviewed studies find that suffering can have an impact on end-of-life decision making, but there are no academic peer reviewed articles that have explored the relationship between suffering and capacity at the end-of-life. There, the outstanding question or issue, is whether the suffering experienced by individuals, affects the legal capacity of that same individual?

This literature review is not exhaustive or definitive because of the diverse nature of these topics. The end-of-life, capacity and suffering of individuals are variable and complex, as are the perspectives of their healthcare providers, caregivers and family members. The qualitative research that follows aims to supplement these limitations by providing a better understanding of these concepts and the connections between them from the perspective of healthcare providers in Ontario.

### **III. HEALTHCARE PROVIDER VIEWS ON SUFFERING AND CAPACITY IN ONTARIO: DISCUSSION<sup>101</sup>**

#### **A. Overview**

In order to address the gap that exists in the literature, namely the relationship between the ability of an individual or his or her substitute decision-maker to consent to treatment at the end-of-life in the context of suffering or even intolerable suffering, we conducted qualitative interviews. A full overview of the qualitative interview methodology can be found in **Appendix A**.

In total, fourteen (14) healthcare providers (hereinafter '**Participants**') from the Greater Toronto Area participated in this research. These 14 participants worked at Toronto Academic Health Science Network hospitals. One of the 14 Participants was from the regional municipality of Hamilton-Wentworth, who worked at a hospital in that region. Represented in the sample were the following Participants (who identified themselves within the following categories):

- 2 Critical Care physicians
- 1 Critical Care registered nurse
- 1 Clinical Nurse Specialist in palliative care
- 1 Respiratory Therapist working in critical care
- 1 Spiritual Care and counselling specialist working in critical care
- 1 Primary Care physician
- 1 Paediatric Palliative Care physician
- 6 Palliative Care physicians

A detailed overview of the findings are set out in **Appendix B**.

The interviews generated three primary findings that we feel will help further the end-of-life discussion, and our understanding of the relationship between suffering and capacity:

- healthcare providers generally did not feel that suffering influenced capacity so as to impair it, but there was broad acceptance that suffering influences patient and surrogate decision-making and providers felt inadequately equipped to assess capacity in the presence of suffering;
- suffering does not just originate from the patient nor is experienced exclusively by the patient – family members and physicians also experience suffering; and
- the end of life care context appears to not fit nicely with the legal notion of capacity (as described in the literature review).

## **B. Provider Perspectives on the Relationship Between Suffering and Capacity**

Our interviews revealed broad agreement among healthcare providers that suffering is a *personal, subjective and highly individual* experience. It is worth noting that while our pilot study sought diversity, it reflects the local experience. It may thus be less relevant in other places, or of more significance to this study, in specific populations where cultural, or religious or other social mores are manifest.

Healthcare providers understand suffering as the final common pathway of numerous processes and feelings. These might include pain, depression, loss of independence, compromised dignity, changes in accustomed social structures such as friends and family, economic concerns, religious and/or spiritual experience, to name a few. Our interviews support frameworks described in the literature that examine multiple dimensions of suffering including physical, psychological and spiritual.

Our interviews found that the relationships between the different forms of suffering are revealed when the individual believes that living is no longer tolerable. Participants felt intolerable suffering was present when there was loss of meaning, or the individual no longer saw value in living in a state of irremediable pain. As in the literature, inability to cope was also cited as a major influence on the tolerability of suffering.

As a result, though the source of the pain in the context of medical care is often physical, those with underdeveloped coping skills are at risk of psychological distress and failing to cope in the absence of psychological or spiritual guidance that can lead to the desire to hasten death.

Healthcare providers in our study emphasized that suffering, as experienced by a person, is dependent on both time and context and the relationship between the elements of suffering are non-linear and change. In other terms, physical pain may dominate one day, spiritual issues later, and loss of a sense of life's meaning at another time.

Providers often felt that the acuity of the underlying disease and pace at which physical suffering emerged played outsized roles in end-of-life care decisions. An acute onset of an illness that allows for very little adjustment time could generate a very different decision by the patient or their surrogate decision-makers than if those same symptoms emerged more gradually.

Health care providers in our sample expressed that they are more comfortable addressing the physical dimensions of suffering than non-spiritual dimensions like psychological distress and ability to cope; they can observe organ dysfunction, and have in recent years become accustomed to assessing physical pain but neither contemporary medical or other health related training, nor the time pressures of clinical practice readily allow nonphysical forms of suffering to be recognized or addressed.

In summary, our interviews found that providers did not believe the presence of intolerable suffering impaired capacity “ipso-facto,” but there are three barriers to addressing (assessing and/or helping to manage) suffering that generates unease among healthcare providers assessing capacity and following end-of-life care guidance:

- providers (physicians in particular) are not well trained to recognize or deal with suffering (compassionate listening was found by participants involved in palliative care to be central, but not something that all providers were necessarily prepared to do, or comfortable doing);
- patients are often unable or unwilling to communicate, or unwilling to receive information that might be considered important from the perspective of the health care provider in order to facilitate informed consent; and
- there is not enough time or resources devoted to helping health care providers address suffering when it is present.

### **C. Suffering is Beyond the Patient**

Our interview participants openly discussed how a patient’s suffering affects two other critical stakeholders groups: clinicians and family-members. Some of the family members may act as surrogate decision-makers further complicating matters.

The healthcare providers we interviewed expressed many challenges working with patients experiencing suffering, including moral distress that made caring for the patient or following their guidance difficult.

The two issues most concerning to providers that caused moral distress were: non-beneficial treatments that caused suffering, and limited ability to have input into end-of-life decision-making.

While all participants acknowledged that what counts as intolerable suffering must originate from the person experiencing the pain, providers expressed concern around what they considered to be non-beneficial treatment that causes suffering as a result of the treatment itself. One provider gave the following illustrative and representative example of a practical manifestation of this issue

*I think we're good at saying, like, you know, 'The CPR part, do you want that? And do you want to be intubated on a ventilator?' Right? But I never hear them explain... bedsores or suctioning or needing a trach or ending up in a chronic facility if they never wake up... they never explain what the whole trajectory could be.*

Their own experiences of providing care that they perceive to inflict suffering on patients at the end of life is a significant source of not only patient suffering, but also their own. For this reason, they expressed frustration that they often have limited ability to have input into end-of-life decision-making for patients, particularly in the context of the intensive care unit.

Providers questioned openly who gets to (and should) decide what non-beneficial care is. It might be tempting to think that requests for futile treatments are indicative of a negative relationship between suffering and the capacity to make decisions but most participants felt this was not the case.

In most non-pediatric settings, participants informed us that the model of care that has been informally adopted is one of patient-centred care. While some clinicians noted that they worked with colleagues who were quite adamant that their job was to advocate and treat the patient only (particularly in the ICU setting), the health care providers in this study described a family-centred approach to care where the dying person was not the only person towards whom care was provided, nor were their wishes the only ones taken into consideration.

This causes several issues for providers:

- conflict between patients and family members could generate conflict between patients and their providers, or providers and family members, both of which impair ability to provide optimal care;
- uncertainties surrounding who the patient is emerge (providers indicated that they sometimes feel pressured to treat the family's suffering at a cost to the patient);

- family member or surrogate decision-maker suffering may lead to a failure to recognize patient suffering or influence the patient's decisions, distressing the care provider; and
- these factors may separately or together cause providers to question directives.

The significance of family well-being for patients cannot be overstated. Just as some patients fear being a burden to family, they have other concerns for family that impact their decision-making. These have been described as patient values by some clinicians: What can be challenging is knowing when the family's influence on the patient's decision-making is problematic in some way. Perhaps it is coercive. Or as one provider suggested, patients will sometimes value their family member's wellbeing over their own.

What came through clearly in these interviews is that the role of family in decision-making, whether it be by the patient or the substitute decision-maker is not straightforward. One clinician who works in the ICU described a situation that was perplexing for the healthcare team:

*... somebody is in a state of chronic long-term care, and has said repeatedly to the whole team, he does not want to continue like this, wants to die, and would appreciate that. And, every time his wife came in, she would meet that with resistance and always turn him, in ten or fifteen minutes, oh, saying, 'No, I want to live and carry on and go on.'... he would never say, in their presence, that he did want to go, and always afterwards, when she was gone or in private conversations, he would 'No, I am tired of this. I am tired of this.'... it's very clear our responsibility to the individual or patient, but when it gets into their circle, their family or, then it just becomes more complicated, and tougher to address.*

While many clinicians described the role of family in decision-making as complicated and fraught, many also described how family plays an important role in alerting clinicians to changes in cognition that might affect their capacity to make decisions at the end-of-life and in the context of suffering.

#### **D. Disparities Between the End of Life Care Context and the Legal Notion of Capacity**

Participants in this study expressed a number of concerns with the importance placed on the legal notion of capacity over other things such as relationships, emotion and other values. As stated by the participants, it is possible that the current cognitive functional model of capacity may not be reflective of how decisions are taken in the context of end-of-life in Ontario because of the impact that suffering has on the ability of an individual to provide informed

consent and the degree to which friends, family and healthcare providers affect patient bedside care. For these providers, this represents some real challenges, particularly in the post-*Carter* era of decision-making.

For some providers, the fact that capacity assessment is not, and likely never will be, an exact science, opens the door to the fallibility of such assessments.

For others, though, the problem is not the philosophical problem of other minds, but rather with the overburdening of autonomy at the end-of-life.

For many patients, the dying process is a process of becoming less autonomous, less in control, and less cognitively aware. To a large extent, the providers in this study expressed concern that the way we have conceptualized capacity in Ontario overburdens a notion of autonomy that does not reflect the relational nature of how decisions are made at the end-of-life. As we have seen, family and clinicians both have great influence over patient decision-making, and this is only sometimes problematic. There may also be values other than autonomy that factor into people's decision-making, such as family harmony.

Part of the problem, according to one participant, is that our society itself has placed too much value in being autonomous, and this could lead to decisions that will shorten life, either because patients refuse assistance, or because they can now ask for MAID before he or she has had time to adjust or adapt to their new situation, or other considerations can be addressed. This is compounded by the fact that other professional values are considered secondary to the respect that professionals pay to patient autonomy.

This is particularly relevant when considering cultures other than that of Western liberal traditions with North American values and thus patients, may find they are being asked to make decisions about things that are completely foreign to them and in a way that is also foreign to their own way of making decisions.

So while culture is one contextual feature that stands out as having an impact on the value that people place on autonomous choices, and on their ability to make decisions in situations that may be completely foreign to them, participants identified other contextual features of decision-making at the end-of-life that have an equal or higher value when compared to a patient's capacity or competence. In order to get to the "right" decisions in end-of-life care, one participant identified the context within which the patient is making decisions, or their caregivers as highly relevant, but not captured by the current capacity model.

*We focus on this, sort of, 'understand and appreciate' kind of model, which I agree is an essential, that's the kind of bare essential. But, I think to, I guess what I would, you know, in my ideal world, I would like us to, (sigh) it's hard. It's hard to think about how – the conversation I'm having in my brain is around how operationally to make the ideal live. But I think ideally, the more we can actually understand and appreciate, about the context, the more we will, and I really do feel like, in practice, we bring a lot of best interests/ consistency with previous wishes, you know, probably some of our own biases et cetera, we bring that to that assessment. So, I think, yes, we need a structure, but I think recognizing what goes around the structure, both as providers, and contextually for the patient, and their caregivers, is essential to understanding whether somebody's really in a good position to make a decision.*



## **IV. Appendix A: Methods and Research Design**

### **A. Literature Review on End-of-Life Research**

The literature review conducted to understand how the concept of end-of-life has been defined is based largely on the definitions and vision in the Declaration of Partnership, as the government and community endorsed commitment to end-of-life care in Ontario. We also searched broadly through World Health Organization publications on end-of-life and palliative care. We then searched publications and education resources produced by major health care bodies in Canada, including the Canadian Medical Association, Ontario Medical Association, College of Physicians and Surgeons of Ontario, Ontario Ministry of Health and Long-term Care, British Columbia Ministry of Health and Cancer Care Ontario. These bodies made reference to the Royal Society of Canada's Expert Panel on End-of-Life Decision Making, and the report of this Panel was subsequently consulted. Searches of HeinOnline, Westlaw Next Canada and QuickLaw (LexisNexis) were conducted for articles on the concept of end-of-life from the perspective of legal scholars. Scholarly articles published in the Canadian Medical Association Journal and the Journal of American Medicine, and publications compiled by the Canadian Academy of Health Sciences were reviewed for medical perspectives on end-of-life. As the topic overlaps heavily with hospice and palliative care, we consulted the websites of relevant organizations including the Canadian Hospice Palliative Care Association, Hospice Palliative Care Ontario, The British Columbia Hospice Palliative Care Association, the Alberta Hospice Palliative Care Association, Palliative Manitoba and Canadian Virtual Hospice. Finally, as many of the sources identified that understandings of end-of-life vary by geography, we conducted a general Internet search for international definitions of end-of-life, and consulted publications from health bodies based in the United Kingdom and Australia.

### **B. Literature Review on Suffering**

The literature review used three interrelated, scoping searches, in order to identify the following bodies of empirical literature such as, qualitative studies on the perspectives of terminally ill patients and/or family members on suffering at end-of-life; and, qualitative studies of patient decision making/capacity to consent at end-of-life.

As the topic of interest spans several disciplines (e.g. philosophy, sociology, ethics, healthcare and law) and a range of disciplinary and methodological approaches, the search will be conducted using carefully chosen parameters, keywords and interdisciplinary databases. JSTOR, Proquest and MedLINE databases were accessed through the University of Toronto library system; MedLINE was chosen because it is a major database for medical, nursing, pharmacy

and healthcare journals, while JSTOR and Proquest are premier databases for sociology, psychology, philosophy and ethics literature.

Further, QuickLaw (LexisNexis), CanLii and other legal websites were used to search case law and related legal documents.

### **C. Literature Review on Capacity**

Unlike the other concepts for which literature reviews were conducted, capacity is clearly defined in legislation. Conceptualizing capacity began with a review of the *Health Care Consent Act, 1996* and the *Substitute Decisions Act, 1992*. To understand how these legislative definitions are applied, we used Westlaw Next Canada, QuickLaw (LexisNexis) and CanLii to identify relevant Canadian case law. We then consulted policies and guidance issued by the College of Physicians and Surgeons of Ontario on how their members should determine whether a patient has the capacity to consent to treatment. Core textbooks in the area of health law, *Canadian Health Policy and Law for Canadian Health Care Administrators*, were reviewed for commentary on this topic.<sup>102</sup> For further commentary and to identify advice given to health care practitioners, we searched for publications by the Ontario Hospital Association, the Canadian Medical Protective Association and the Advocacy Centre for the Elderly. For an international perspective, we consulted positions on legal capacity to consent from the United Nations High Commissioner for Human Rights and the United Kingdom National Health Service. Finally, we reviewed past Law Commission of Ontario publications that have surveyed the legal framework for capacity and its implications.

### **D. Qualitative Interview Methodology**

In this study we employed standard individual in-depth interview methodology for collecting insights from healthcare providers. Individual, in-depth interviews are most appropriate for this study as this can be a sensitive topic which is best suited for a one-on-one interview where confidentiality can be better managed than in a focus group setting. Also, an in-depth understanding of the relationship between suffering and capacity is best gleaned from individual interviews of a personal nature.

#### **1. Conceptual Framework**

Qualitative research methodology requires the use of sensitizing concepts drawn from a conceptual framework for analysis of the data. A theoretical framework has been developed

using the work of Erik Cassell<sup>103</sup> Arthur Frank<sup>104</sup> and Arthur Kleinman<sup>105</sup>, as well as Jennifer Nedelsky's work on relational autonomy<sup>106</sup>.

## **2. Data Collection: In-depth Interviews**

We conducted 14 interviews with participants at times and locations convenient for participants, between May 6, 2016 and June 3, 2016. Interviews ranged from 60-90 minutes and were conducted at a time convenient for the participants. As interviews progressed, interview guides were modified to reflect emergent themes and participant concerns, in keeping with this kind of naturalistic inquiry where participants and qualitative researchers are collaborators, "using questions, answers, and probes to better understand how and why things work."<sup>107</sup> (See Appendix X for the Interview Used). The University of Toronto Research Ethics Board provided its approval for the study's involvement of human participants.

We used a combination of purposive and convenience sampling. These are forms of non-probability sampling appropriate to qualitative research. Participants are chosen not for their representativeness but for their relevance to the research question. In qualitative research, one is more concerned to ensure that the sample is indicative (as opposed to representative) of a phenomenon or setting, and one must collect enough data to make meaningful conclusions about the phenomenon of interest. Sampling is therefore progressive and theory-driven. It is therefore impossible to talk about the ideal sample size in qualitative research, but researchers often consider they have a large enough sample once "theoretical saturation" has occurred, which in this study happened around the 12th interview but two additional interviews were conducted. Saturation occurs when researchers are comfortable that the properties and dimensions of the concepts and conceptual relationships selected to render the target event are fully described and that they have captured its complexity and variation. Theoretical saturation is the endpoint of theoretical sampling, and is achieved through "constant comparison" analysis.<sup>108</sup> However, given the very short timeline for this study, convenience sampling was employed, including snowball sampling from study participants.

## **3. Sample Description**

In total, 13 clinicians from the Greater Toronto Area participated in this research. These 13 participants worked at Toronto Academic Health Science Network hospitals. One participant was from the regional municipality of Hamilton-Wentworth, who worked at a hospital in that region. Represented in the sample were:

- 2 Critical Care physicians
- 1 Critical Care registered nurse
- 1 Clinical Nurse Specialist in palliative care
- 1 Respiratory Therapist working in critical care
- 1 Spiritual Care and counselling specialist working in critical care
- 1 Primary Care physician
- 1 Paediatric Palliative Care physician
- 6 Palliative Care physicians

#### **4. Data Analysis**

Interviews were transcribed verbatim, and checked for accuracy. Transcripts were subjected to an inductive thematic analysis according to standard interpretive techniques. This involves the iterative development of descriptive codes that are grounded in the participants' own words using the method of constant comparisons, and the combination of conceptually-related descriptive codes into broader conceptual themes.

Constant comparison analysis, when combined with theoretical sampling, allows for the development of analytic themes that are “tightly integrated and tied to its supporting data.”<sup>109</sup> In this kind of qualitative analysis the researcher identifies categories, situations, and analytical dimensions. By combining theoretical sampling and constant comparison the rigour of the study is improved. This approach will be used to look for emergent themes that are made visible by using the conceptual framework as a theoretical lens through which to interrogate the data. In this way, data speaks to theory, and theory speaks to data.

## **V. Appendix B: Summative Findings of Healthcare Provider Views**

Participants in this study have spent their professional lives in the presence of suffering. While the goal of their work is to redress suffering, many of them have observed that it is inherent to the experience of being human, and in this sense it is something to which we are all vulnerable.

How we understand suffering has huge implications for what we do about it, and how we think it influences end-of-life decision-making. While there is an impulse to categorize suffering into different typologies in order to render it visible and curable, one of the major findings is that the clinicians who participated in this study all agreed that even though we may be able to distinguish between different forms of suffering, these different kinds of suffering are inextricably intertwined. Not only this, but suffering is a subjective experience, which makes any attempt to study it objectively profoundly difficult, if not also morally problematic. When it comes to intolerable suffering, participants had a variety of views on what would make suffering intolerable from their observations of patient perspectives. Participants also had a variety of views from their own perspective as providers who are sometimes asked to provide care that they perceived to be non-beneficial and that they also perceived to increase suffering.

Suffering alone was not thought by the participants to affect the patient's decision-making capacity in the absence of a cognitive impairment. The role of the patient's family in decision-making at the end of life, and the integration of the family into the circle of care of the dying person were considered significant factors in how decisions are made at the end of life. And while advance care planning was thought to be important, particularly by the clinicians who work in critical care medicine, advance care planning was also thought to be highly problematic by others. This has to do with the observation that not only does suffering fluctuate over time, but so, too, do patient choices and preferences. This led many to problematize what they thought to be the overburdening of patient autonomy. In addition, a patient-centred-care model in these contexts is often rejected in favour of a family-centred model, which has implications for whose suffering is really being addressed in the context of the decisions that are taken by clinicians, but more importantly, by the patients themselves.

### **A. Types of Suffering**

Participants in this study were asked to comment on whether or not they distinguished between different forms of suffering, including pain, other physical forms of suffering (such as shortness of breath or nausea), psychological, existential, or spiritual suffering. While most felt that we have a fair amount of success in recognizing and dealing with physical pain, the non-physical forms of pain were thought to be problematic, to some extent. For two clinicians, the

term “existential suffering” was new to them. Although there is no clear consensus on the term,<sup>110</sup> it is generally understood by the participants to refer to suffering related to impending death, and loss of meaning for the patient.

For some, the difference between spiritual and existential suffering was a matter of the patients’ world views and whether or not one holds religious beliefs. However, some thought there was a difference between existential and spiritual suffering:

*Existential would be more meaning related, to me, more ‘why’ questions. ‘What’s the meaning of this?’ Where spiritual distress may not be asking those meaning questions. They may already have a sense of meaning or purpose or why, but just finding that a difficult road, if you will. So existential would be, ‘I don’t know what the road is’, spiritual distress would be, ‘The road is hard.’*

Existential suffering was thought by one clinician to pose a particular challenge for small children because of the difficulty in explaining what happens when one dies, and where one will be after death. In addition, children experience distress at the thought of going somewhere with their parents. Adolescents, whose developing independence and sense of self is thwarted by terminal illness, can also experience existential suffering:

*I think you can get stuck in the ‘Why has this happened to me?’ And that can then turn into anger, and anger (I’m sure, this probably isn’t so different with adults) but I’m thinking particularly at a time in adolescence where children are striving to seek independence, if I’m just sort of learning to take care of myself, and make my own decisions and I’m, my desire is to pull away from my parent and to listen more to my peers. And then I get this illness that starts dragging me back into the role of the sick child, needing Mom and Dad to care for me.*

It was widely believed that the non-physical aspects of suffering, such as psychological suffering, existential and spiritual suffering, are not well addressed or even understood, particularly in the context of critical care. Palliative care has moved towards addressing these forms of suffering, but still has some way to go:

*We really haven’t paid it [existential suffering] a good deal of attention. And I would say that within the medical profession there are other social scientists who have been paying attention to that, but we haven’t necessarily been connecting and we certainly haven’t been training most healthcare providers in how to recognize and how to have a language about it—how to ask questions about it—and how to acknowledge and deal with their own personal suffering as a starting point.*

### **1. Barriers to Addressing Suffering**

As in the case of existential suffering, many felt that clinicians are not well trained to recognize or deal with suffering more broadly conceived. Communication about suffering is challenging, and there is a lack of training and resources for dealing with suffering, particularly in the context of palliative care that takes place in the home. Compassionate listening was also found by participants involved in palliative care to be central, but not something that all clinicians were necessarily prepared to do, or comfortable doing.

### **2. Communication**

Many clinicians observed that even speaking about suffering was difficult or impossible for some patients. Also there may be things patients do not want to know about their condition and its possible remediation. One participant suggested that it is important to ask patients what they don't want to know as much as it is important to ask what they do want to know. Recognizing that patients have a choice about what information to hear from physicians can be difficult if the physician really thinks the patient ought to know. These observations are interesting because they point to the difficulties in addressing suffering when patients are unable or unwilling to communicate, or unwilling to receive information that might be considered important from the perspective of the clinician in order to facilitate informed consent.

It was widely acknowledged, however, that listening to patients was crucial to being able to address suffering. Indeed, listening itself was considered therapeutic:

*Sometimes, we can't make it better. You know? We can't fix all forms of suffering. But we can certain make them worse. And it's amazing how just a few minutes of active listening, and allowing people to express themselves, without judgement, without trying to fix it, trying to make it better, try to cheer them up, can change a person.*

*...more of the work is in talking things through, and in developing a better understanding of what is actually happening for that person, at that time. And that in itself tends to be very useful for patients*

### **3. Time, Training and Resources a Constraint**

Many people mentioned that a main barrier to addressing non-physical suffering was time:

*But I wonder if we do miss [suffering] sometimes, by not sitting down and taking time. And not everybody has the time to do it.*

*But to a major degree, we also don't dig too deeply into it a lot of the time, simply because we feel like it will be low yield. We feel like it will be very time consuming and potentially a difficult exploration for the patient, and maybe for ourselves too, as healthcare providers, because it's hard not to see parallels with your own life.*

In addition, a lack of training in addressing suffering, particularly from a palliative perspective, was viewed as problematic:

*We need to find a way to ensure that all clinicians are comfortable, not all clinicians, but most clinicians are comfortable with sort of like, frontline exploration of suffering. Because right now, we don't do that in our training. And I will tell you that for a lot of clinicians, the moment they get a whiff of suffering, they start backing out of the room...So that's what I'm hoping, from the clinical side, that we will, we will have more training in that.*

Even if clinicians were better able to take the time to recognize and explore suffering, the resources at their disposal to deal with suffering are limited:

*And I think if you ask the population as a choice, 'Would you rather have access to good palliative care or have access to hastened death?' I think the majority of people would say access to palliative care. But it's not, it's not a 'sexy topic' to talk about. And so where we're left with is still big hole, gaps in palliative care. Like, when I go to see a patient, when I get a new consult, one of the first things I do before I go to see the patient is I check where they, I map them on Google Maps. I look at where they live, because that's actually going to change my care plan for them.*

*So I would say, as a physician, pragmatically, it's sometimes not my, I either don't feel like I have the time and resources or maybe the skill to do it well, and sometimes, in the home, in particular, we struggle to actually find the right resource to bring into that situation.*

## **B. Different Forms Of Suffering Are Interconnected**

By now we can see that the remediation of suffering is complicated by a number of contextual factors. The very nature of suffering itself, however, is such that the typologies we have developed for differentiating one form from another can be helpful for clinicians to recognize suffering, but at the end of the day, these typologies belie the fact that suffering is a complex phenomenon that is not necessarily reducible to biology nor easily quantified.

*Well, yes, I can enumerate [different types of suffering]. Do I think it's all that helpful? Not really. Because it's very unusual to exist, for example, just existential*



*suffering, without having some, you know, physical impairment, that also affects your ability to function socially, that then affects your mood, and affects how you see yourself in the world and that may challenge the ideas that you had of how the world works. So yes, there are different ways of looking at it, which might be helpful in terms of making sure that you have addressed the whole person but I don't see that they exist in exclusion.*

The relationship between physical suffering and nonphysical suffering seems to be something participants agree upon: there is a relationship between the two that is not easily explained or treated. However, they also agree that dealing with physical pain is usually the most important thing to treat first:

*I think those definitions are probably helpful in terms of trying to explore with patients and families, what the issues are or what's driving suffering. But, I would say, clinically, in my experience, it's often not a single thing, right? It, these things are very much overlapping and influence one another and are interrelated. So, I think it's helpful to get a sense of, with a patient, which is greater or lesser, in their mind. I would also, I guess I say that often is physical suffering is front and centre, if you don't deal with that, it's very hard to deal with any of the rest...*

While it is not always clear how different forms of suffering relate to one another, as we know from the studies of physical pain, the way that it is perceived by patients is entirely subjective. As we shall see, there is widespread recognition of the subjective nature of suffering by the clinicians participating in this study.

### **C. Suffering Is Subjective**

There was consensus amongst these clinicians that suffering was a subjective phenomenon. This was true for all forms of suffering, including the concept of intolerable suffering that has become so central to conversations about physician assisted death. When asked, 'How do you know when someone has suffering?' one clinician said succinctly what many other participants expressed:

*They tell you...until we get a tricorder that reads this thing we are stuck. We're stuck, sadly, with listening to the darn patient. And we have no other choice but to listen to them and accept what they say...the patient knows better than anybody what they're feeling.*

There was widespread consensus amongst participants that even though suffering might be evident in patients at the end of their lives, it is not always, and even with their years of clinical experience they can be surprised by patients:

*It's a mystery. You know? And we're always taught that you trust what the patient's assessment of their suffering is. You know, people can talk to me, and they can look like you're looking right now, like, comfortable and not in pain, and tell me they're ten out of ten [on a pain scale].*

When asked about what makes patient suffering intolerable, many clinicians said that intolerable suffering is something only the patient can determine:

*Intolerable suffering, I mean, ultimately that has to be something that a patient determines for themselves, what's intolerable, 'What can I not tolerate? What can I not live with?*

*I guess just their personal expression of it. That's all I can see is just, you know, it would be as simple as 'I can't take this anymore. I can't take this anymore.' And heard often enough, expressed enough ways, that we get that. We get that message.*

For some clinicians, intolerability is also gleaned from the number of times patients express their suffering's intolerability, or from the durability of the expression after prolonged attempts to remediate suffering:

*And that's, that's their new reality, and that's what they're living with, no. I think if this is a sustained request, based on this new experience that can't be fixed, they're commenting on how their new reality is impacting their life and that's their assessment. It's not like this acute moment in time and then we fix it. If it's really not fixable, and they've, we've tried whatever we can to help them cope, and they're continuing to live with this, and tell us that this is intolerable to them, and that's their assessment, then I think we have to go with that.*

*I think it's so personal, right? I don't think that you can tell me what my intolerable is and I can tell you what their intolerable is. I think I have to decide for myself, what's intolerable for me, which is, like, I don't think that makes that any easier, because if I'm having a bad day, and all of a sudden decide, 'This is intolerable' but then tomorrow, 'Oh wait, no, I can tolerate this.' Like there has to be some check points. But, yeah, I think it's that progressive, like, it's not going to, like, each day is going to be worse than the next and then deciding where that lies. So, yeah, I think it does need to be something that's kind of progressive, right?*

While suffering may be subjective, and intolerable suffering something that only the patient can evaluate, clinicians were able to talk about what, from their own perspective makes suffering intolerable for patients.

## **1. Factors that are Perceived to Make Suffering Intolerable**

For some participants, intolerable suffering was suffering that has no meaning. While it is not a widely held view that patients value suffering, some do question the relation between suffering, value and intolerability. For one participant, suffering can have instrumental value, but that has to be a person's own view:

*I think there's an instrumental value to suffering, that, that it can lead you to insights. It can lead you to knowledge that will help you later. When it, you know, when people talk about, a lot of people talk about this, again, in the context of an assisted death, as, you know, 'Why would you want to stop suffering? Like, why is suffering such a bad thing?' Well, I say, 'Look, I mean, that's fair. I mean, there are some people who would want to look at suffering as an opportunity to grow as a person and learn more.' And I respect that...But there are many people for whom they will look at their situation; they will look at the amount of time they have left to live and the degree of their suffering, and say, 'Well, nothing, in my mind, I'm not going to learn anything or I think my likelihood of learning something is so low, that I'm perfectly willing to forego whatever life I have left, because I just don't see why any of this would be of value to me.' And I think that has to be a personal decision.*

The concept of functioning and coping was also central to some people's ideas of what makes suffering intolerable:

*I think it would be hard to imagine somebody highly functioning, um, I guess it would be hard to imagine somebody with tolerable suffering, who is highly functioning, requesting an assisted death. I would have trouble seeing that. I would think that this person would probably only want an assisted death if it was intolerable or very functionally affecting, right, and/or, you know, functionally impairing.*

Often clinicians mentioned the fear of being a burden to family as relevant to the intolerability of suffering as well, particularly for people who were of a certain personality which has difficulty with loss of control over their life as well difficulty in letting others care for them.

While some may believe that suffering has value for some patients, which affects their perception of intolerability, it was more common for the participants to express the belief that suffering becomes intolerable when it ceases to have meaning for them:

*Well, loss of meaning, loss of function, intractable pain, loss of meaning is a big one. And that's the one that I've done the most thinking about. Ah, where you have no reasonable expectation of restoring, in your life, the very things that made life for you.*

*...intolerable is when we have no meaning attached to it [suffering] and no reason to go through it. So, for instance...if I put you through incredible suffering, to take a kidney from you, to give to a child, and said 'You can't have any pain meds. You can't even have any anaesthesia for your surgery.' You'd do it probably, for your child, right? And, that pain and that, what you went through, would be meaningful for you. You know?... So I think what makes it intolerable is that there's no meaning and no vision for even seeing meaning somewhere down the road...*

Relatedly, another participant observes that existential suffering plays a large role in people asking for assistance with dying:

*They're most existential factors, actually. Because people will tolerate actually a lot of pain, even. And it becomes a very individual thing, when that pain becomes so intolerable that you actually want to die. It's very, very, very rare for someone to say 'You know, I'm in such pain that I would like to end my life.' And I have actually never seen that happen, without that person also having a lot of existential components added on... And, the existential factors can exist, of course, on their own, without pain. But when you have any physical pain, then there tends to be a compounding of that pain, by the existential problems.*

So not only is suffering subjective, participants perceive that patients find suffering becomes intolerable when there is a loss of meaning in the suffering, or that there is no value to be found in continuing in a state of irremediable pain. Suffering is also a complex phenomenon that requires a holistic approach to treatment. What also became clear in these interviews, however, is that a holistic approach to suffering must take into account that both the family and clinicians involved in end of life care are also suffering.

This becomes significant, when we see later that in some very important ways, the Western liberal notion of autonomy upon which the legal notion of capacity is based does not take into account that patients are significantly, and not inappropriately, influenced by family members' concerns, concerns for family, and the views of clinicians.

First let us turn to the evidence that suffering is not only located within the subjective experience of the patient: both clinicians and family are also suffering when patients reach the end of life.

#### **D. Clinicians Also Experience Suffering**

We have seen from some of the quotes presented so far, that clinicians will often mention their discomfort around patient suffering. Some participants mention their own suffering explicitly:

*When it gets really hard to be in front of that suffering is when patients can't acknowledge it, because it's too scary for them. So you can't reach them. I had a patient once, who every time that we talked about our concern around what was going on in her body, she would start to cry... And I found that really hard, and very draining. I mean, it's, the thing that's hard about that suffering, like, the existential suffering is, you know, those of us who are sensitive to that stuff, I mean, it's going to trigger your own stuff, right? It's going to trigger my own fear of death, my own fear of losing people I care about and how much do I want to be in front of that all the time?*

*In fact, it's very hard for the clinicians, whether it's a nurse, a pharmacist, a physio, doctor, it's to care for those types of patients when you're, when they're uncomfortable. You go 'Oh what can I do here?' And you yourself, I think, have anxiety generated based on, you know, being in a room with somebody who's clearly suffering, that you need to do something, and you want to do something about it, and feel the need to do something about it. So that will impact you as well.*

*I think we, and it's cumulative. Right? I think in palliative care we are around a lot of sadness. And so, there's, and it can, I'm sort of thinking about your question from a slightly different perspective, which is that I think there is a self protection mechanism that sometimes kicks in, where it's like, 'I can take anymore.' Right? 'I can, I know you're suffering and I know that it's, I would like to help you, but I can't go there right now. Cause I just don't have the internal resources to be there with you at this point.*

While often clinician suffering is described as making it difficult to perform their job, as in many of the quotes above, sometimes clinicians describe how it makes the identification of patient suffering easier:

*I also use, the other thing I use with students is I will ask them 'How is that interaction making you feel?' Because I think for me, when I'm, when I can feel myself, you know, this is all that sort of mindfulness stuff, but I mean, when I can feel myself reacting and being drawn in and feeling, you know, sad, distressed, powerless, anxious, wanting to withdraw, like, all these sorts of things that it generates in us, are often clues, I think, to the fact that there's real suffering going on here.*

*And then, also, to be aware that, to reflect on how you're feeling when you're with the patient. Because, the funny thing, and I know this is discussed in formal, much more academic ways, but the funny thing is that if you're starting to feel a certain way when you're with the patient, chances are they are feeling that way too.*

By far the largest source of clinician suffering that was described by participants, however, was the moral distress felt when patients or families asked clinicians to do things they felt were causing more suffering for futile ends. This occurred primarily in the context of critical care.

## **1. The Problem of Suffering Resulting From Medical Care**

While all participants acknowledged that what counts as intolerable suffering must originate from the person experiencing the pain, clinicians expressed a huge amount of concern around what they considered to be non-beneficial treatment that causes suffering as a result of the treatment itself. Their own experiences of providing care that they perceive to inflict suffering on patients at the end of life is a significant source of not only patient suffering, but also their own. For this reason, they expressed frustration that they often have limited ability to have input into end-of-life decision-making for patients, particularly in the context of the intensive care unit.

*I think there is suffering on the caregiver as well. I think we don't spend enough time thinking about how we support the care provider. And in particular, I mean, some of the cases that I've been involved in, there was a lot of moral distress amongst care providers, and how we support them in their decision, how we build their skill sets to communicate, coping mechanisms when they feel like they're being in positions that conflict what they see as morally responsible behaviour or care. You know, there just is not a lot out there. We went through a lot in one of our ICUs, in terms of developing a mindfulness program amongst our nurses. And it has helped immensely to allow them to deal with these difficult scenarios, these difficult situations.*

Whilst acknowledging the problems that perceptions of non-beneficial care pose for clinicians, one participant raised the question of who gets to decide what non-beneficial care is, whilst acknowledging that their perspective might be different because they do not provide hands-on care:

*Futile treatment is huge. But, again, who decides when it's futile? Who decides what is valuable or how much life is valuable? And sometimes, we think we're providing futile care and then, somebody surprise us and humbles us, right?*

One intensivist explained that of all the people who should be able to speak to a patient's level of suffering, and how it should be factored into decision-making at the end of life, it should be them:

*It takes a lot for an intensivist to switch that switch and say 'Crap, you know, what am I doing?' Right? (laugh) That is not our training. It's becoming more and more a part of a bigger reflection of what it is that we're doing, as our field becomes more conscious of what we can achieve and what we can't. And that's a good thing... don't brush off the doctor. Probe it. Why is the doctor taking this stand? That's a good question, right? Because it's a hell of a lot easier to keep doing it, and to fold your cards, and just do whatever everybody says, than to put yourself out there and say 'No, I'm going to fight this one.'*

## E. Does Suffering Clarify or Cloud a Patient's Judgement?

While some participants, when asked if suffering clouds or somehow impairs judgment, reacted with a top-of-the-head response of saying that it does, once participants had a chance to talk for a few moments about this, they clarified their statements to say that it could influence, not necessarily impair judgement:

*And I, for sure, one hundred percent, I think that it's going to impair someone's ability to sort of make decisions. Like, the lady with, that I saw last week, who's like, 'Okay, well, that's it. I don't want anything more. Just send me to the palliative care unit.' Right? 'I don't want anything more done.' And then this week, she's – although, you know, now that I'm saying this out loud, maybe it's not so much that it impairs our capacity, um, so much as we just need to be careful because maybe that's the, that was the right decision for her, in that moment in time. And the next week, a different decision was more appropriate for her...Right? So, maybe it's not so much capacity more so, it's just like, we just kind of need to keep checking in with patients.*

Most participants found this a difficult question to answer in an abstract way:

*I find that a tough question, because it removes capacity from the context of the person, in a way that, it makes good sense in one way, because you want to imagine, so far as I know, the concepts are built around the idea of a rational decision maker, sort of seeing all the options in front of them, and making a choice, almost as if they're stepping outside of their life a little bit. But, the fact that they're in that suffering, it is part of the context, and so maybe it actually, not so much clouds their decision making but influences their decision making in a way that is entirely reasonable, because it is part of the context. And so, I don't know exactly how to address that question, when I think about it myself.*

In the case of intolerable suffering, and whether or not it was more likely to impair decision-making, participants thought for the most part, again, that it was an important influence, but not necessarily an ipso facto impairment to competent decision-making:

*It could. I think that's a possibility [that intolerable suffering would be more likely to impair decision-making]. I think the intolerable suffering is also part of the decision making, right? ...just because they have intolerable pain doesn't mean that they're making the wrong decision, right? Because we have to get away from that, because that is exactly what we're saying, intolerable pain means you have the option to make this decision. So, we can't say 'Because you have intolerable pain, you can't make this decision.*

Other participants felt that suffering was considered not to be problematic in other contexts in end-of-life care, and therefore it should not be in the context of requests for MAID:

*Why I think it's important to broaden this discussion again, because some people have said that, 'Well, you know, when someone's suffering and in the throes of depression or you know, in the throes of physical impairment, of, you know, severe physical symptoms, that they're not capable of consenting to things, because their capacity is impaired. I reject that notion. I think we do accept that people can have quite significant symptoms but still be capable of deciding what is and is not in their best interests. And I would, I push, I put it back on those people to say 'I don't think you actually believe that suffering impairs capacity for the simple reason that you and I and all of us have followed patients' decisions on what might seem life and death decisions, all the time, because of suffering, not in spite of suffering.*

Another participant found that they just could not say one way or the other:

*It's a really hard question to answer. It's a really hard question to answer. Because, again, our assessment of capacity, we can only talk about capacity when you're not in that state, because none of us can really appreciate what it's like to be in that state. And so, I, we, I don't think any of us can answer whether that... I think it does change the way you look at things, but would it, can I honestly say that I think it would impair someone's capacity? I don't know. I don't know.*

It was clear, however, that for some participants, having some kind of psychiatric disorder would be problematic:

*I guess the question is, is that decision still a sound decision and should it be respected? And I think likely, yes, with the exception of the fact of having, the black and white part is the having a psychiatric disorder.*

This last participant went on to clarify that what they meant was that a cognitive impairment of some kind would preclude sound decision-making.

For one participant, intolerable suffering was thought to clarify patient wishes:

*Actually, when I'm in intolerable pain, I really know what I want! ... Just because they have intolerable pain doesn't mean that they're making the wrong decision. Because we have to get away from that, because that is exactly what we are saying: intolerable pain means you have the option to make this decision [to end your life]. So we can't say, 'Because you have intolerable pain, you can't make this decision.*



However, there was, as mentioned above, widespread agreement that because suffering can affect judgement, suffering needs to be redressed to the extent possible prior to any requests for MAID.

## **F. Families don't Perceive Patient Suffering**

The clinicians in this study often described situations in which family were making decisions on behalf of the patient, but because of their own suffering were unable to recognize the suffering of the patient. This presented particular challenges for clinicians who could perceive patient suffering where the family could not:

*...we have been involved in cases where...to be able to work with families and stay involved in the care has resulted in a care plan that caused great moral distress to healthcare providers. And that's almost always doing, continuing to do things to keep the child alive, past the point where healthcare providers think that it's reasonable, and one or two of those cases have also involved family not wanting us to use medication for pain relief in the way we would normally use. We don't give it out like candy, but, um, and sometimes, there is a cultural belief that a certain amount of suffering has to happen to enable you to enter the afterlife. That wasn't, that happened in another case, not the one that I was just thinking of. It was, I think it was the family's unwillingness to see pain, because if they saw pain, they would have to accept that what we were saying was true.*

*There are people who become so consumed by the experience and what they're going through and the loss and the suffering that that entails that when they're acting as substitute [decision-maker], they can't decide. They're paralyzed... I can tell you, they have the ability to understand. They have the ability to appreciate. But they don't have the ability to see.*

Suffering might be a barrier to family perception of suffering in the patient, but one clinician speculates that it is because they haven't been in this position before, and cannot see the future:

*...we think that the patients are really suffering and we should be withdrawing care or making those decisions and the family doesn't. And I think that's hard on us, 'because we think they're suffering, and I don't know if the family doesn't notice it or I'm sure they care. It's not that they don't care...I think for us, it's knowing, or thinking, what the future is going to- what the next day, week, months are going to look like...So maybe a family member looking at that is like, 'Maybe it's not so bad.' But I know in my head, that this is going to be weeks and months and it's never going to get better ... And now as I'm saying this out loud, I realize maybe that's why family members can't see it as well, or don't see it as soon as we do, because they don't necessarily know what the future looks like.*

This raises questions again, about the quality of the informed consent for end-of-life treatments and how prepared substitute decision-makers are to provide informed consent in the absence of relevant clinical information.

## **G. Involvement of Family in Decision-Making**

It was also thought important to bring the family along, so to speak, so that conflict could be avoided, but also to make sure that patients, whose competency to make decisions might be questionable, have the family there to make sure that the care plan is the right one for the patient:

*...dealing with a few patients who are off breathing machines, and you talk to them and develop a relationship with them on the floor, then they, as sick as they can be, you want to make sure that you hit them at the right time. I think you want to make sure that you've got other family members there as well, at the same time, so that they can see. Because they'll say 'Well, a plan is being developed and we weren't involved, so it can't be, possibly be valid.' But, again, you want, when the patient gets sick enough, you can't the substitute decision maker to witness what's gone on, because the care plan you want to implement, they're going to go, 'I'm seeking your consent for the care plan, because that's what the patient wanted.' And they'll go, 'Yeah, that's what this patient wanted.'*

The significance of family well-being for patients cannot be overstated. Just as some patients fear being a burden to family, they have other concerns for family that impact their decision-making. These have been described as patient values by some clinicians:

*I think that another value that many patients have is, I would call it family harmony. So how does my decision impact the family. And that can go both ways. So that can go the way of 'Okay, well, my family's not quite ready for me to go, so I will accept this chemo that I really don't want.' And it can also go 'Well, I don't want to burden my family.' Without being able to hear that the family aren't burdened and actually value this time. So, I think it does, for people who do have families that are functioning and non-conflictual, it hugely impacts the decision making.*

What can be challenging is knowing when the family's influence on the patient's decision-making is problematic in some way. Perhaps it is coercive:

*I think the greatest challenge is actually we often talk to patients, and they say what they want, and then, family members will come in and you know, not be accepting of their decisions, one way or the other. And, so you get this kind of dance, right? Because then the patient will say 'No, actually, I've decided I'll go ahead with the chemo.' just to give an example. You know? They'll have a conversation with the team and find out their cancer's now metastatic, very limited*

*quality of life. The chemo probably will hold it off for a few weeks, maybe a couple of months. 'Do you really want to go through months and months, like, is that how you want to spend your last two months or should we just sort of do our best to keep you comfortable?' And the patient will say 'Oh no, I don't want it.' da, da, da. And the family will come in and say 'But, you gotta fight. You gotta fight.' You know? And then, 'Oh yeah, I'll fight.' (laugh) So that to me, is the biggest challenge... And what constitutes undue influences in those circumstances?*

What came through clearly in these interviews is that the role of family in decision-making, whether it be by the patient or the substitute decision-maker is not straightforward. One clinician who works in the ICU described a situation that was perplexing for the healthcare team:

*I'll give you a classic scenario. I shouldn't say classic, but this is something that happens- where somebody is in a state of chronic long-term care, and has said repeatedly to the whole team, he does not want to continue like this, wants to die, and would appreciate that. And, every time his wife came in, she would meet that with resistance and always turn him, in ten or fifteen minutes, oh, saying, 'No, I want to live and carry on and go on.' So obviously where our moral distress weighs very heavy, and this was over almost two years or so, of this. And it was probably from six months or so, that the gentleman in question was expressing a wish not to go on, not to be kept alive. And he would see his wife for two or three or four hours a day or so. And, but we weren't sure necessarily, (laugh) how much joy he took in that, but he felt some responsibility to her, and the family, that it would, it would change his, (sigh). I don't know if his position was changed, but it changed how he expressed his wishes. And he would never say, in their presence, that he did want to go, and always afterwards, when she was gone or in private conversations, he would 'No, I am tired of this. I am tired of this.' And never, we could never get into the, (laugh) ah, the psychodynamics of the relationship or family or it was just something that we were uncomfortable with. It's our responsibility was to him, really. But you know, we weren't, but, and that's actually probably an area that we do a poor job at, or not always a great job at, at these kind of family conflicts. And you know, we don't, it's very clear our responsibility to the individual or patient, but when it gets into their circle, their family or, then it just becomes more complicated, and tougher to address.*

However, when another participant had this story relayed to them in their interview, they had a very different response to the response of the person who told this story: it wasn't so much a question of a family conflict, but rather a patient's internal tension between two competing values:

*He has different values. When he's alone, and he's probably scared, or not, he might actually feel more distressed with his wife, because of her distress... So I mean, it sounds like there's that conflict between 'How do I best look after my wife?' and 'How do I best look after myself?' And if it might have been framed that*

*way, because it probably wasn't. It was probably framed in terms of the decision for withdrawal.*

For this clinician, questions around patient capacity have to be placed within the context of the goals of care and patient values:

*...but to have these kind of values discussions and clarify those values into goals, then you have the decision that includes a capacity piece. But that big piece often doesn't happen, and the assumption is often made that 'Well, of course people want longer. Of course.' So they don't even, you know, point to other values that may be supported by different choices in the treatment. So, I think that's a definite piece that could be much improved.*

So capacity could be much more contextualized, and put into a broader conversation about end of life.

*Into a broader relationship and into a broader conversation about goals, about values and goals of care.*

From the pediatric perspective, the concern was more about the effect of decision-making by family who are not necessarily the best influence:

*The situation's unfortunately, for some kids, who may have parents who are not the best role models, are they going to be influenced by the adults around them? And again, as human beings, we're all vulnerable to the influences of people who are close to us. But I think children, in particular, because of the developmental stage they are in will be vulnerable, more vulnerable.*

Of course this raises some questions about the relational nature of autonomy, and whether and to what extent autonomous decision-making, in the Western liberal tradition of autonomy, makes sense in light of these data. However, we will return to this.

### **1. Family Important for Identifying Changes in Cognition**

While many clinicians described the role of family in decision-making as complicated and fraught, many also described how family plays an important role in alerting clinicians to changes in cognition that might affect their capacity to make decisions at the end-of-life and in the context of suffering.

*But they'll sometimes alert us to subtle changes in cognition that we might not pick up because we don't know the patient as well. Or, recently, a family-member told*

*me that he [the patient] was having visual hallucinations and seeing things on the walls, and he hadn't told me anything about that. So sometimes patients will disclose things to their family members. And then other times, they'll disclose them to us and not their family. But I find family really helpful in assessing orientation sometimes, in people that don't communicate well, or don't or just aren't interested in having big conversations with you. I find family really helpful in assessing where somebody is at cognitively.*

## **H. Factors that Affect Patient Capacity at End of Life**

While participants were certain that medications can impact a person's capacity, including medications to relieve suffering, they did say that the effect of medications is difficult to predict:

*Anything that has the tendency, had the capability to cause delirium, obviously has the possibility of causing like, of impacting capacity. So steroids, for some patients, can send them into a bit of a mania, can send them into a bit of a psychosis... So I'd say most cases, steroids would not worsen their capacity and may, in fact, improve -Yeah. There's, no, I don't think there's a single drug, save for, like, if you sedate the patient completely -would you be able to say in advance, if it's going to impact their capacity.*

*So, we're pretty, um, cautious with our doses. You know, like, we start really small, and then if they don't have a response, we go up a little bit, a little bit. So we're pretty cautious. But, it gets tricky, because it depends on how close to death people are. So if they're in the last weeks to months of their life, they can turn and decline at any time. And we don't know when that's going to be. Sometimes, we think we do know, but as an illness gets worse, especially in cancer - it's so easy to talk about cancer, 'cause it's a bit more predictable. But it affects level of consciousness and cognition and that's going to happen anyway, without the opioids. So, was it the opioids, or was it the illness? And a lot of people blame opioids on changing cognition. And they certainly can.*

One of the most often mentioned impairments to patient capacity at the end of life is delirium. This can be caused by a number of factors, including the natural course of the dying process, constipation, electrolyte imbalance or analgesics, according to one participant. It is also a significant source of patient suffering:

*So up to 70% of patients in the ICU will experience delirium, So it's a big challenge. It's a combination of things, we're thinking. And we tease it out. It's a combination of drugs, disrupted sleep, medications. Infection will cause it. Being out of their environment; the geriatric population is especially prone to it. Lack of sunlight, so the causes are multi, you know, dementia will cause people to have delirium quicker and make it harder to - so there's all these factors, but within that, you know, if the team isn't aware it's delirium and then treats it with more pain meds, then, you get more delirium, right? So you can get this cycle, if people aren't saying*

*'Oh, wait a minute. They're having these behaviours and this strangeness.' that can come with that.*

Fortunately, participants felt that ICUs are getting better at dealing with delirium:

*I do think in the last little bit, we've gotten better and looking at things like, delirium and stuff like that, and that kind of brings up, like, 'Oh, they might be totally capable. They're just experiencing delirium.' And maybe patients in the past we've deemed incapable of making decisions and it's really something that we could have fixed in a day or two. So, that's interesting. And I think we could, like, we're getting better at it. We're getting more aware of it, and that is interesting.*

However, just the dying process itself can cause fluctuations in capacity and consciousness and the ability to communicate:

*Cause capacity does change, as, and I've never thought of this before, but it makes sense, as an illness gets worse, as people get sicker and weaker and more fatigued and they're not eating, and there is more risk for delirium, at the end of life. And then, people are just so tired, like, they're not actively engaged anymore. And, and fatigue, and they can't have these conversations. They can't. It takes too much focus. And as people get sicker, everything slows down. And their ability to speak changes. It takes a lot of energy to talk.*

This is why most of the clinicians, conveyed the importance of the quality of relationship between the person assessing patient capacity, and the patient.

## **I. Capacity Assessment Best Done in Context of a Relationship**

As we saw previously, clinicians often relied on family members to clue them into changes in patient cognition. It is these kinds of inconsistencies that can only be noted by those who know the patient well. Therefore, many participants felt the person best suited to assess capacity was the clinician who knows the patient the best in order to apprehend the nuances:

*Well, we don't place much value on the relationship in which these questions get asked. And so, it kind of becomes a contractual relationship. 'Do you fit, do you understand; do you appreciate?' rather than recognizing that that whole discussion and the whole, I mean, because capacity doesn't come just about capacity. It's within the context of a healthcare decision. So, within all of that, it's a very relational thing.*

*...can I say the ideal? Somebody who's sufficiently connected to understand the dynamics and sufficiently distanced to not be unduly influenced by those relationships. I mean, that would be the ideal, somebody who knows you, but is*

*also, you know, has a professional distance. I think the problem with formal capacity assessment is you're bringing a stranger into the situation. So, sometimes I think a lot of the nuances get lost in that process, recognizing that you have to have something. And, by the same token, if you're too invested, I think there's, yeah, potentially to be, to miss stuff...*

### **1. Treatment plans best done by those who know that patient best**

Many clinicians also placed importance on the quality of the relationship with the patient in devising a care plan when they are at the end-of-life and experiencing suffering. Again, knowing the patient well means that clinicians are able to tell when requests don't fit with past desires of patients, and that might indicate either a problem with capacity, or an new, acute episode of some form of suffering that is impacting capacity for decision-making. One clinician described a patient who was requesting treatments that the health care provider believed to be non-beneficial whilst in hospital where she didn't know care providers very well, but upon her return home was able to make (what the clinician considered) better decisions. Another clinician placed importance on consistency with past wishes, as well as consistency with their past decisions in order to have decisions make sense. For many of the clinicians in this study, part of that story involves factors other than just rational, un-coerced decision-making, and for this reason they often spoke about how the legal notion of patient capacity is not the only relevant factor in decision-making at the end of life.

## **J. Problems with Capacity Assessments at the End-of-Life in Suffering Patients**

Participants in this study expressed a number of concerns with the importance placed on capacity over other things such as relationships, emotion and other values. As stated by the participants, it is possible that the current cognitive functional model of capacity may not be reflective of how decisions are taken in the context of end-of-life in Ontario because of the impact that suffering has on the ability of an individual to provide informed consent and the degree to which friends, family and healthcare providers affect patient bedside care. For these clinicians, this represents some real challenges, particularly in the post-Carter era of decision-making.

These finding confirm the trope that clinicians only question capacity when the patient expresses something that does not align with their own thinking:

*Well, I think a lot of it is, and realistically, I joke about this with people, but I think the number one screening test for capacity is 'The person disagrees with me.' So if I propose something, and the person says 'No', I will...there's always a couple of neurons firing in our brain and say 'Oh my gosh, well, is he capable?' Can he—how does he not see the wisdom of what I'm suggesting? ... If somebody's agreeing with*

*my, with the brilliant things I'm suggesting, then clearly, something must be going right in his brain. Right? And it never occurs to us than an incapable person would agree with us.*

*We think if you're not making the choice I would make, you're not being reasonable.*

For some clinicians, the fact that capacity assessment is not, and likely never will be, an exact science, opens the door to the fallibility of such assessments:

*And you know, all of this being said, capacity is far from an exact science and I'm always-in the shadow at the back of my mind—I always doubt my own reasoning. And Cheryl Misak's<sup>111</sup> narratives about ICU psychosis, about people looking like they're completely rational and being completely unhinged, but being so smart that nobody can tell—that haunts me.*

*Usually though...the staff are very good at having the discussion with the patient, trying to involve the patient, and (sigh) I mean, it is almost a different, an instinct for whether they are exhibiting capacity to, you know, if they can't stay on track with something, it's probably not the time to do that conversation.*

For others, though, the problem is not the philosophical problem of other minds, but rather with the overburdening of autonomy at the end-of-life.

### **1. Overburdening of Autonomy**

For many patients, the dying process is a process of becoming less autonomous, less in control, and less cognitively aware. To a large extent, the clinicians in this study expressed concern that the way we have conceptualized capacity in Ontario overburdens a notion of autonomy that does not reflect the relational nature of how decisions are made at the end-of-life. As we have seen, family and clinicians both have great influence over patient decision-making, and this is only sometimes problematic. There may also be values other than autonomy that factor into people's decision-making, such as family harmony, as we have already seen.

Part of the problem, according to one clinician, is that our society itself has placed too much value in being autonomous, and this could lead to decisions that will shorten life, either because patients refuse assistance, or because they can now ask for MAID before he or she has had time to adjust or adapt to their new situation, or other considerations can be addressed. This is compounded by the fact that other professional values are considered secondary to the respect that professionals pay to patient autonomy:



*Well, we don't place much value on the relationship in which these questions get asked. And so, it kind of becomes a contractual relationship. 'Do you fit, do you understand; do you appreciate?' rather than recognizing that that whole discussion and the whole, I mean, because capacity doesn't become just about capacity. It's within the context of a healthcare decision...we don't value the relationship between the healthcare provider and the patient as we're having these conversations. We don't value that enough. We tend to, it's all about autonomy. It's all about autonomy. And we're not valuing beneficence or non-maleficence, and they are values that do need to enter into this as well.*

Another person thought that the dying process itself leads to less autonomous decision-making:

*I mean, autonomy is really a myth, in a way, I think anyway, in that we're very much affected by what's going on around us. So, and to have an isolated autonomous act, I think, anyway, is not a, is really not something that is possible. And we do become, I think it's natural as well, to become more dependent as we get older, and certainly as we get more ill. And we're not used to that, as a very autonomous society. We don't like that very much. But it is a fact of life that we don't go from, you know, running a marathon to then dying comfortably in our bed. You know, just go to bed one day at a hundred; you're run your marathon and then you die. It's not really, doesn't happen that way. You have a gradual process of getting more and more dependent, and many of us want to skip that step, but once you're in that, then it becomes a different point of view, I think.*

Another clinician identified that in palliative care there is a different philosophy which is less about being able to control the manner of death autonomously, and more on caring for people in the moment:

*Because, you know, the philosophy around palliative care is very different from the philosophy, sort of underlying hastened death, which is very much around autonomy, having control over things, when you feel like you won't be able, when it's not, going to be tolerable for you. It's very forward thinking, right? Whereas palliative care, it's very much like yes, there's some advance care planning. You know, like, 'If things don't go the way we want, what's our plan B?' But it's also, very sort of day to day, 'How do we make each day the best it can possibly be?' Right? 'How do we maximize your quality of life from day to day?' So, the philosophies are very different, although they aren't, like, mutually exclusive. Like a patient, it's not that if a patient is pursuing hastened death, that they can't also receive palliative care at the same time.*

While different clinical areas may have different cultures, as the person above alludes to, we also have to take into consideration that there are different traditions and cultures of decision-making around the world that impact how patients respond to being asked to make their own, autonomous decisions.

## **2. Impact of Culture on Decision-Making in End-of-life and Impact on Suffering**

Another issue that clinicians identified is that people from cultures and traditions other than that of Western liberal traditions, and North American values may find they are being asked to make decisions about things that are completely foreign to them and in a way that is also foreign to their own way of making decisions:

*It would be, it would actually be odd to try and say 'Okay, okay, but if you had to make it all on your own and with nobody here, what would you decide?' The person may not even understand that question. As, in, let's say someone's elderly, in Toronto, we have people from all over the world here. Often, the oldest generation in the family are the people who have spent the longest time away from Canada are now coming in, and so they're the least likely to sort of fit that, probably, North American, or at least Western model. And so it may not fit so well.*

*I think I bring a particular perspective in the sense that having worked in a place like, (African country name) where decisions, where autonomy is—I mean, yes, in principle, there's some autonomy rights that need to be considered. But, generally decision making is collective. And, people, the autonomous decision, you know, as an outsider, seems to be, 'We make this decision together.' So, it's not the only way that the decisions get made. And I would say, even working in East Toronto, you know, I see every, sort of, you know, cultural background one could imagine. And so they bring that to the table. Right? How do we make decisions? What's our cultural context for decision making? So I do, I think I understand why, you know, not that I know that much about it, but if we take the sort of Western tradition of rights and things, and say that, you know, autonomy is like this, almost this trump card, it's not that way everywhere.*

## **3. Context and Capacity**

So while culture is one contextual feature that stands out as having an impact on the value that people place on autonomous choices, and on their ability to make decisions in situations that may be completely foreign to them, participants identified other contextual features of decision-making at the end-of-life that have an equal or higher value when compared to a patient's capacity or competence. In order to get to the "right" decisions in end-of-life care, clinicians identified other set of factors or concerns:

*We focus on this, sort of, 'understand and appreciate' kind of model, which I agree is an essential, that's the kind of bare essential... But I think ideally, the more we can actually understand and appreciate, about the context, the more we will, and I really do feel like, in practice, we bring a lot of best interests/consistency with previous wishes, you know, probably some of our own biases et cetera, we bring that to that assessment. So, I think, yes, we need a structure, but I think recognizing what goes around the structure, both as providers, and contextually for*

*the patient, and their caregivers, is essential to understanding whether somebody's really in a good position to make a decision.*

Another participant identified as a concern that sometimes patients may be deemed competent, but they are making decisions out of fear, which engages a different part of the brain than the frontal cortex, where rational decisions are made:

*And then, you know, I think that Paul Gilbert<sup>112</sup> has done something called compassion focused therapy, originally for trauma victims...And that's, so Paul Gilbert has really highly influenced my thinking. And he really simplifies neuroscience in a way that I teach patients. And so what he will tell us is that the big picture way of looking at the brain is that it consists primarily of three emotional systems. The first system is the most primitive. It's in our brain stem. It's our threat system, and it's mediated by adrenaline. So fight, flight or freeze. And when we are in our threat system, we are not utilizing our frontal cortex. Our thinking is very limited and it's all about 'How do I make myself safe?' So if someone is in their threat system, and worried about dying a horrible death, it might make sense in that to say, of course, 'Hastening my life is going to make sense. That's going to, it's going to get it all over with.' ... So in terms of capacity, I think if somebody is in their threat system, they might make a decision that is different than they would if they were actually in the wise part of the brain, not feeling isolated and alone, feeling connected to other people and connected to their own strength.*

Perhaps, then, the discipline of neuroscience can help us understand better the kinds of decisions that patients take at the end of life, and how better to support their ability to understand and appreciate.

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## VI. Endnotes:

- <sup>1</sup> *Criminal Code*, RSC 1985, c. C-46; *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (Royal Assent, June 17, 2016). [Criminal Code]
- <sup>2</sup> *Health Care Consent Act*, 1996, S.O. 1996, c. 2, Sched. A.[HCCA]
- <sup>3</sup> *Ibid*, s. 4(1).
- <sup>4</sup> *Carter v Canada*, 2015 SCC 5.
- <sup>5</sup> *Ibid* at, para 4.
- <sup>6</sup> *Criminal Code*, *supra* note 1, s. 241.2(1).
- <sup>7</sup> *Ibid*.
- <sup>8</sup> John Fraser, *Palliative and End-of-Life Care Provincial Roundtable Report: a Report from Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care* (March 2016): 4, online: [http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative\\_report.pdf](http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf). [Fraser]
- <sup>9</sup> *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action*, (December 2011) at 34, online: [http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care\\_report.pdf](http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf). [Advancing Palliative Care]
- <sup>10</sup> World Health Organization, “WHO Definition of Palliative Care,” online: <http://www.who.int/cancer/palliative/definition/en/>.
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