

# Negotiating End-of-Life Decisions

## Entangled Repertoires on the Intermittent Paths of Acute and Palliative Care

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**Abstract:** When someone is very ill in Canada, the individual is taken under charge of the medical system and put on one of two distinct paths for handling the situation: either acute or palliative care. In the acute path, all available medical technology is deployed to save lives and avoid death, while the main objective of the palliative path is comfort, as death becomes inevitable and expected. The two paths are ordinarily seen as part of a linear process, wherein acute care is initially deployed and palliative care only after acute care is determined ineffective. In practice, however, the two paths are intermittent, as the reasoning repertoires that guide care practices along both paths are constantly renegotiated by care teams. This article follows the decision-making process regarding the use of the ventilator for two individuals at the end of their lives as their care teams alternate between legal, curing, and care repertoires. The entanglement of these repertoires leads to unexpected care practices as patients are shifted from one path to another. In both cases, the transition from acute to palliative care was nonlinear, and the purposes of the possible medical actions that could be taken along the two paths kept changing as events unfolded.

**Keywords:** Acute care; palliative care; end-of-life decision-making; ventilator; care pathways; ethics of care; Canada

**Résumé:** Au Canada, quand une personne est gravement malade, elle est prise en charge par le système médical et orientée vers l'une des deux approches distinctes pour gérer la situation : les soins intensifs ou les soins palliatifs. Dans le cas des soins intensifs, toutes les technologies médicales disponibles sont mises en œuvre pour sauver des vies et éviter le décès, tandis que l'objectif principal des soins palliatifs est le confort, le décès étant inévitable et attendu. Ces deux voies sont généralement considérées comme faisant partie d'un processus linéaire, dans lequel les soins intensifs sont initialement déployés et les soins palliatifs sont uniquement mis en place si les soins intensifs ont été

jugés inefficaces. Dans la pratique, cependant, ces deux approches sont intermittentes, car les raisonnements qui guident les pratiques de soins dans les deux cas sont constamment renégociés par les équipes soignantes. Cet article suit le processus décisionnel concernant l'utilisation du respirateur artificiel pour deux personnes en fin de vie, alors que leurs équipes soignantes alternent entre les raisonnements juridiques, curatifs et de soins. L'imbrication de ces répertoires conduit à des pratiques de soins inattendues, les patients passant d'une approche à l'autre. Dans les deux cas, la transition des soins intensifs aux soins palliatifs n'était pas linéaire, et les objectifs des actions médicales possibles qui pouvaient être prises dans le cadre des deux stratégies changeaient constamment au fur et à mesure que les événements se déroulaient.

**Mots clés :** Soins intensifs ; soins palliatifs ; prise de décision en fin de vie ; respirateur artificiel ; parcours de soins ; éthique des soins ; Canada

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## Introduction

Dying and death are transitional times, often lacking clear indicators of when the dying process begins (Jordan, Price, and Prior 2015; Kaufman and Morgan 2005). The liminal period becomes even more complex as patients and their family members navigate the various possibilities offered by the healthcare system. On the one hand, care teams want medicine to work miracles to keep patients alive, but on the other hand, nobody wants to prolong life to the point where patients end up in a limbo, neither completely alive nor deceased (Kaufman 2015). However, the boundaries between the two states are often blurred, as they depend on which care paths patients are on, which in turn depend on what end-of-life decisions are being made by medical practitioners and family members (Kaufman 2005). A “care path” is a generalized way of identifying how the medical system will manage patient care. Two care paths can be taken in Canada when patients seem to be approaching the end of their lives: acute and palliative. Patients are put on the acute care path when a life-limiting condition has not (yet) been identified; this path typically requires patients to be admitted to an intensive care unit (ICU). Admissions to an ICU are never done directly, meaning it is done by another unit in the hospital where the imminent death was determined, and mechanical ventilation may be initiated. The palliative care path occurs only when a life-limiting condition has been identified, such that the patient is expected to die soon, and their family chooses to limit the types of interventions medical

professionals would take to keep them alive (Levoy, Tarbi, and De Santis 2020). Researchers theorizing about care paths and identifying points of transition from acute to palliative care have pointed to a linear model in which the two paths are clearly defined and separated, and do not go in reverse order (Rosa et al. 2022). However, this is not what happens in practice in hospitals. In this article, I argue that both paths are intermittent and that a person on the palliative path may be returned to the acute path as decision-makers deploy different styles of reasoning, which I call “repertoires,” to guide the choice of care path.

Different repertoires are constantly being deployed and negotiated among healthcare professionals and patients’ family members as they make “end-of-life decisions.” The “end-of-life decision” is an umbrella term encompassing various actions medical professionals must take to respect the autonomy of patients and their family members. The two most frequent “end-of-life” decisions made in the ICU in Canada are either to withhold or withdraw treatment. “Withholding” occurs when a patient or their proxy has chosen not to pursue treatment, often by providing a Do Not Resuscitate (DNR) or Do Not Intubate (DNI) order (Marcoux, Michara, and Durand 2007, 238). “Withdrawing” only occurs after a treatment has been initiated and then a decision is made to remove the treatment and “let nature take its course” (Marcoux, Michara, and Durand 2007, 238). While “treatment” can include anything from artificial nutrition to providing cardiovascular medication, treatment in this article is exemplified by mechanical ventilation. This medical intervention is used to assist or replace spontaneous breathing when a patient is unable to breathe adequately on their own and involves a machine called a ventilator (Epstein and Truwit 2011). The ventilator delivers air to the lungs via a tube inserted into the patient’s mouth, called an intubation. This procedure can be done anywhere. However, once intubation and mechanical ventilation are initiated, patients have to be transferred to the ICU. When mechanical ventilation is withdrawn, the same tube must be removed; this procedure, called extubation, is typically done in an ICU (Epstein and Truwit 2011). It is during those moments of decision to withhold treatment (by not intubating) or withdraw treatment (by extubating) that acute and palliative care paths become intermittent, sometimes resulting in unexpected care practices. This article follows two patients, Bruno and Henry, who both began on the palliative path, but, due to the entangled repertoires of decision-makers, were sent to acute care before returning to the palliative path.

## Theorizing Medicine in Action

This project draws on Latour's (2005) Actor-Network Theory (ANT), where he argues that the possibilities for action in social interactions are not limitless; rather, a range of possible actions only becomes feasible through the interactions of different actors within a network. Actions are not performed in isolation but are always mediated through interactions with other human and non-human entities. Thus, the potential for any action is shaped and enabled by the network of relationships in which an actor is embedded. For instance, a piece of technology (a non-human actor) can open new possibilities for human action by providing new tools or capabilities, but it can also constrain or direct actions in certain ways. A network is thus a series of entangled, interconnected ramifications; researchers must untangle them to describe its associations. Latour also distinguished between "intermediaries" and "mediators" in these networks. Intermediaries simply transmit meaning or force without altering them, whereas mediators actively transform, translate, distort, and modify the elements they carry. The transformative capacity of mediators introduces unpredictability and novelty into the network. Mediators do not merely facilitate actions but redefine what actions are possible. By following mediators, researchers can trace how actions are made possible or impossible and how social realities are constructed and reconfigured.

Although Latour (2005) provides some guidelines on what mediating entities researchers should study, ANT does not identify the reasoning processes that make different sorts of actions possible for actors. I adopt Mesman's (2008) concept of "repertoire" to fill in the theoretical gap. In analyzing medical decision-making processes in a neonatal intensive care unit (NICU), Mesman (2008, 36) defines "repertoire" as "a particular style of reasoning; as such it functions as a guiding principle that orders our ideas about what the world is and how it works." Repertoires indicate which concerns will become central versus peripheral in any particular situation, and thus help legitimize and clarify decisions (Mesman 2008, 36). Mesman (2008) identified four types of repertoires in the NICU: "cyclical" and "linear" repertoires are used to establish a prognosis, while "situational" and "case-based" repertoires inform decisions. In a cyclical repertoire, the course of events is conceived as following a precise path in which past, present, and future are part of a single temporal system and function as fixed moments in a natural cycle (Mesman 2008, 59). This cyclical structure makes the future predictable and inevitable. By contrast, time is not conceptualized as unilinear in the linear repertoire. Arguments based on the

past as determining the future are rare, so the linear repertoire is more open. This leaves the future uncertain—either completely unpredictable or tied to probabilities—so prognosis may diverge in various directions. In a situational repertoire, the present condition becomes central, while the past and future have less significance (Mesman 2008, 32). Finally, in a case-based repertoire, the patient's condition is related to other similar cases; that is, the present is relative to the past, while the past is connected to similar situations (Mesman 2008, 39). In sum, Mesman (2008) focuses on the temporal framework of care and the influence of repertoires on prognosis and decision-making to provide a nuanced view of how time and case comparison impact medical reasoning.

Although Mesman's (2008) four repertoires were instrumental in his analysis of decision-making in the NICU, they were too meta-level for my research on end-of-life decisions. I focused on uncovering action possibilities to understand transitions between palliative and acute care. Observing medical actions (not intubate, intubate, extubate) with elderly patients, I categorized the reasoning around these actions as based on legal constraints, life preservation, or patient comfort. This led to identifying three repertoires: legal, curing, and care.

The legal repertoire includes actions allowed by formal rules and regulations, from national laws to unit-specific protocols. The rules may be implemented nationwide (for example, Criminal Code of Canada), at the provincial level (for example, Health Care Consent Act of 1996), or as unit-specific protocols operating only at the institutional level. The curing repertoire involves actions to maintain or save life, while the care repertoire involves actions to relieve suffering. Decision-making often involves all three repertoires, but they can contradict or entangle each other. Untangling these repertoires provides a better understanding of how acute and palliative care paths intersect and are negotiated by all actors involved.

## **Methodology**

I met Bruno and Henry (pseudonyms), both patients in the ICU, during six months of ethnographic fieldwork in an ICU in a hospital in Ontario, Canada, in 2016, where I was conducting research on decision-making around the use of the ventilator. Ethical approval was obtained from the University of Ottawa (case # H03-15-15) and the hospital on condition of anonymity. All principles of ethics were and are being respected. I followed 15 individual patients during 705 hours of observation and spoke with 121 people, including physicians (MDs), nurses (RNs), allied healthcare professionals such as respiratory therapists (RTs),

hospital administrators, and patients' family members. I adopted an interactive approach by conducting informal interviews (often within focus groups), replacing non-participatory observation with active listening, and recording fieldnotes, including conversations among medical staff and family members, during or immediately following observations (Chou 2015). This methodology allowed me to observe reactions and obtain insights from individuals during rapidly changing medical events with uncertain outcomes (Chartrand 2022). The conversations and actions analyzed here using the repertoire concept illustrate exceptionally well the ways in which palliative and acute care paths can become intermittent.

## **The Withholding Treatment Decision: To Intubate or Not to Intubate?**

### ***Bruno: When Advance Directives are Unknown***

I first encountered Bruno in the ER, at which time he was intubated and attached to the mechanical ventilator. Once a patient is ventilated, they are automatically transferred to the ICU. The following conversation occurred between the physician who was covering the ER (MDER) and another doctor who was covering the ICU (MDICU) that day.

MDER: Bruno was admitted to intensive care two weeks ago. During his stay in the ICU, he had two cardiac arrests and was resuscitated both times. After a week, we were able to get him out of intensive care, and four days ago, he was transferred to a long-term care facility. During his time in the ICU, I was taking care of him, and the POA [Power of Attorney, Bruno's son] wanted us to do absolutely everything necessary to keep him alive, even if we thought that palliative care was a better care plan for him. But now, as I was reading the discharge notes from the ward, I found that the son had agreed to make his father DNR and put him on a "no admission to ICU" order. I only read this after I intubated him. Today, his level of consciousness was decreased. The long-term care facility sent him to the emergency room. When he arrived in the emergency room, white fluid was being suctioned from his airways. He had likely aspirated from his feeding tube. Since I knew him from the previous ICU admission, I intubated him immediately. But I realize now that I shouldn't have done that.

MDICU: So what you are telling me is that right now we are completely going against the son's wishes?

MDER: He is currently intubated, though the documentation indicates not to intubate him and not to admit him to intensive care. It does not indicate that I can extubate him or admit him to the ICU. What do you recommend me to do?

MDICU: Because you intubated him, we have no choice but to admit him to ICU and provide him with all other medical treatment available to make him better while we are waiting for the son to answer us.

As MDER explains, Bruno had previously been in the ICU, which means that he has already transitioned at least once from the acute care to palliative care path in the past. His statement that “the POA wanted us to do absolutely everything necessary to keep him alive,” indicates that he decided to intubate Bruno in the ER based on Bruno’s son’s curing repertoire. This contradicts the healthcare professionals’ care repertoire. They reasoned “that palliative care was a better care plan” for Bruno so he would be kept comfortable until he dies, which seems relatively imminent since he had already been resuscitated twice and could no longer breathe on his own when he was admitted to the ER. The legal repertoire—represented by the son having power of attorney—is also omnipresent in this situation. The MDER refers to obeying the POA’s wishes to keep Bruno alive back at the first ICU admission and then mentions that the POA opted for a DNR/DNI and “no ICU admission” order once Bruno was well enough to be moved from the ICU to the long-term care ward. Following these orders as part of the legal repertoire should have ensured that the care repertoire would be prioritized, while possible actions that could be taken under the curing repertoire would be limited. That is, no extraordinary measures would be taken by healthcare professionals to preserve Bruno’s life: they would not use the ventilator or any other treatment requiring ICU admission.

Although legal documentation was changed to ensure Bruno would remain on the palliative care path, these changes were not evident to the healthcare team when Bruno was sent back to the hospital from the long-term care facility, as MDER notes: “I intubated him immediately. But I realize now that I shouldn’t have done that.” The medical team defaulted to acting based on the curing repertoire as understood from Bruno’s previous admittance to the ICU. Now they are confronted by the problem of whether to withdraw the ventilator and transfer Bruno from the ER to the ICU. When the MDICU says, “we have no choice but to admit (...) while we are waiting for the son to answer us,” he is drawing on the legal repertoire, since healthcare professionals must obtain

consent to withdraw ventilation. Without consent, they must continue to act based on the curing repertoire.

If the DNR document had been properly recognized, the healthcare professionals could have shifted to the care repertoire. This is suggested by the ER doctor and nurse (RNER) when I spoke with them right after Bruno was transferred to the ICU later that day:

MDER: In the emergency room, I was really caught between a rock and a hard place. I always told myself that I would treat my patients as I would want my parents to be cared for. I wouldn't want anyone to do to my father what we're doing to Bruno. But on the other hand, I don't want to lose my job. I didn't want to intubate Bruno. I wanted to give him medication to make him comfortable so he could die peacefully. I wanted to provide him with palliative care. But legally, did I really have any other choice but to intubate him? This is pure and simple therapeutic obstinacy. However, in this type of decision, our opinion as doctors is completely ignored. Look at what happened to the doctor at Sunnyvale with the Rasouli case<sup>1</sup>. It's the family who decides, not us.

RNER: One would think that today, with palliative care and discussions about euthanasia, we as healthcare professionals could choose what is best for the patient based on their medical history and current condition. In practice, this is not the case. We need consent for everything. I would rather say that we need consent only to provide comfort care and to let nature take its course. Because without consent, life must be saved. Otherwise you no longer have a career, and you risk being sued. So I am appalled by the situation....but I love my job and intend to keep it.

In this passage, MDER states that he would not have chosen to intubate one of his family members if he were in a situation like Bruno's, reiterating the preference to prioritize possible actions that are in the care repertoire rather than the curing one. However, MDER also speaks to his obligations to obey the legal repertoire involved in making such decisions when he asks, "But legally, did I really have any other choice but to intubate him?" Knowing that in the past, Bruno's son would not have consented to withholding treatment, he could not assume it would be any different this time, and therefore decided to stay within the action possibilities of the curing repertoire. Since the orders were about withholding care (not withdrawing treatment), this meant the MDER was

bound to keep Bruno on the acute care path. He justifies his decision by citing a legal case where the court ruled in favour of the Rasouli family in stating that consent is needed to withdraw treatment once it has been started. The nurse echoes the legal repertoire when she emphasizes the importance of proxy consent, that is, family members consenting to take action when ventilated patients are unconscious, as is typical at this point in the end-of-life stage. Without obtaining proxy consent, medical professionals can be severely sanctioned even if they have provided excellent care. Although the nurse deploys the care repertoire in arguing that consent should only be necessary to “let nature take its course,” the legal repertoire prevails; only the curing repertoire can be used to guide practices, unless healthcare professionals know a DNR/DNI exists. And even then, such documents do not guarantee a patient will not be moved back onto the acute care path.

***Henry: When Power of Attorney Goes Against Advance Directives***

I first saw Henry when he had just been admitted to the ICU after being moved from the ER, where he had been treated for pneumonia by being given antibiotics. The ventilator was not being used to assist him in breathing. After morning rounds, the ICU doctor (MDICU<sub>2</sub>) invited me to observe a family meeting with Henry’s three sons and a daughter, all of whom had POA. That meant any one of them could make decisions about Henry’s care with or without the approval of the others. This portion of the discussion is from the beginning of the meeting:

MDICU<sub>2</sub>: We are here to clarify what you want us to do regarding your father’s care. If I understand correctly, your father is 97 years old. He has a diagnosis of severe dementia and is currently living in a nursing home. There was a DNR and a DNI order in his file.

Henry’s son (HSON<sub>1</sub>): I’ll stop you right there! I don’t understand why he had that order. I am his power of attorney, and I was never informed about this.

MDICU<sub>2</sub>: I went back to check his file. The document was signed two months ago when he was last admitted to the hospital. He had refused to undergo a surgical procedure, and the question was addressed at that time. He was the one who signed the document; it was his choice.

HSON<sub>1</sub> clenched his fists on the table: My father suffers from dementia, and you think he’s capable and in the right state to sign that kind of document? I find that absolutely appalling. You should’ve seen the

state he was in yesterday. On top of that, because of that document, you didn't even want to help him. He was struggling to breathe, he was suffering, and no one wanted to help him. He was dying, and no one... [Henry's son stopped speaking as his eyes filled with tears and his hands trembled.]

MDICU2 responded softly: Your father has a chronic medical condition and is elderly. Pneumonias are very common in people with dementia. People with dementia often die from pneumonia, not from their dementia.

HSO<sub>N1</sub>: I know my father is old and has a lot of medical problems. I know he won't live much longer. I accept that. But there's a difference between keeping him comfortable and just letting him die....It was like he was drowning in the emergency room and ... you did nothing to help him until I said I was removing the DNR and that I wanted everything done to save his life. So I want it to be clear that if he gets out of here, I don't want him to be DNR, because I want intervention if he's struggling to breathe like that again.

When MDICU2 explains that pneumonia is a common cause of death in people with dementia, he is drawing on both care and curing repertoires. The curing repertoire is invoked since pneumonia can be healed by the administration of antibiotics. The DNR/DNI documents Henry signed do not prevent medical professionals from employing this kind of treatment. Indeed, giving antibiotics and other medications as an attempt to heal falls within the limitations of the actions provided by the DNR/DNI as components of the legal repertoire. The care repertoire also comes in where medication is provided to alleviate pain. However, the MDICU2 also alludes to the curing repertoire being limited by the legal repertoire, since not all possible medical technology (such as mechanical ventilation) is being deployed to prevent death. The DNR/DNI set limits to what is permissible within the curing repertoire, in this case, intubation. This limitation is what made Henry's son so upset. He interpreted the medical team's obedience to the limitations imposed by the DNR/DNI documents as a refusal to help his father and alleviate his suffering, that is, put him on the path of palliative care. Henry's son explained to me later what had happened in the emergency room:

I saw that he was having difficulty breathing; it was like he was a fish out of water. That's when I started asking questions. The nurse told

me that he was on antibiotics, but that he seemed to have passed the point where just antibiotics would work. I asked for medication to help him. She said she had just given him some and that he would get another dose in three hours. I asked her what they usually did in these circumstances. She told me that they usually intubated. But since he was DNR, they didn't consider giving him that treatment, and he was going to die like that. That's when I got angry. You don't let a human suffer like that....I know he's going to die soon and that he doesn't have long. But dying like that is not humane.

Henry's son drew on the care repertoire when he demanded his father be intubated to relieve his suffering, though not to prevent his death. Describing his father's labored breathing as like a "fish out of water" suggests he may have heard the so-called "death rattle" that often occurs toward the end of someone's life, and which sounds like patients are suffering even when they are unconscious (Chartrand 2020). Henry's son urged intubation now so his father could die without suffering later as a legitimate course of action, reflecting the care repertoire. Thus, actors can operationalize repertoires in different ways that sometimes create conflicts between family members and healthcare professionals, especially when the same repertoire provides different action possibilities. Indeed, the medical professionals were already taking permissible action according to the care and legal repertoires by withholding mechanical ventilation but giving pain medication and antibiotics to Henry per his consent on the DNI. Nevertheless, for his son, the repertoire of care legitimated intubation and, as one of the POAs, he had the legal power to move Henry onto the acute care path. As we see in the next section, transitioning back to the palliative care path comes with another entanglement of repertoires.

## **The Withdrawing Treatment Decision: To Extubate or Not to Extubate?**

### ***Bruno: Negotiating with Time***

A week after he was readmitted to the hospital, put on the ventilator, and moved to the ICU, Bruno seemed well enough to be extubated. However, the physicians were reluctant to extubate without clear instructions from Bruno's son. The ICU doctor explained the situation to a physician in residency (RESMD):

MDICU: After a two-hour conversation, they reached an agreement. We have the right to extubate Bruno. If Bruno stops breathing or has a cardiac arrest within two hours of extubation, we must do everything

to resuscitate him. If he has a cardiac arrest more than two hours after extubation, we do nothing: we let nature take its course. All because the son believes that withdrawing treatment is a form of euthanasia. He doesn't want to be responsible for his father's death. Refusal of treatment is easier for him to accept than stopping treatment; the two hours gives him the comfort he needs to ensure that stopping treatment had nothing to do with his father's death.

RESMD: So we're giving him the best possible chance. Respiratory-wise, he's on minimal support. He could be extubated today, based on what you think.

MDICU: Knowing what's going on with the son, it has nothing to do with science and medicine. This is what I call the art of medicine. This patient is extubatable. He could have been extubated on Friday, Saturday, or Sunday, except no one wanted to extubate him because of legal concerns, not because he wasn't medically ready. I just started [my shift] this morning. If I extubate him today and he codes during the night, I'm afraid the son will come back at me with legal procedures and blame me for his father's death. So I say we should wait another day. At least tomorrow it seems like I will have more information and more reasons to extubate him. He's tough as a rock. I'm sure he'll still be alive for weeks.

According to MDICU, Bruno's son does not want to be responsible for his father's death, so he operationalizes the curing repertoire by attributing meaning to the time between withdrawing life-support (extubation) and death. If a death event such as cardiac arrest occurs within two hours after extubation, he will perceive the cause of death as due to withdrawal of treatment, so he should be immediately resuscitated. In that two-hour liminal zone, healthcare professionals must follow the action possibilities of the curing repertoire. However, if death occurs more than two hours after extubation, the son will accept that the cause of death is Bruno's incurable medical condition. He then puts limits on the actions that can be taken to cure his father (save his life) and prioritizes the care repertoire. The son has used the repertoires to establish when death might be caused by something over which he and the medical team can have some control.

The MDICU then draws on the legal repertoire to inform his decision to wait another day or two before extubating Bruno, when he says he wants to

avoid having the POA, Bruno's son, "come back at me with legal procedures and blame me for his father's death." Bruno is thus mechanically ventilated longer than he would have been if healthcare professionals were adhering strictly to either the care or curing repertoire.

Not being able to practice the way they truly believe would be best for patients at the end of their lives is distressing for healthcare providers, as the doctor, nurse, and an RT in the ICU expressed to me after morning rounds:

MDICU: These are difficult situations for the entire team. We're forced to do things that go against our knowledge. Medicine is the only profession where you're forced to do something against your expertise. Do you tell your electrician how to handle your electricity? No! But I am forced to continue prolonging the suffering.

RNICU: He's a vegetable. He has no chance of surviving. He's going to die. We don't know when. What we're doing is therapeutic obstinacy. We are preventing him from dying...What bothers me is that we are prolonging the suffering.

Bruno was extubated the next day. After two hours had lapsed, the action possibilities that were guarded by the legal repertoire collapsed, leaving a space for the care repertoire to provide guidance again. At this point, the healthcare professionals contacted Bruno's daughter, which they had not done before I asked the nurse why they hadn't contacted her earlier:

RNICU: I hadn't called her before because she wasn't the legal representative, and I didn't want us to have legal problems. However, now that he is in palliative care and is dying, I think she should come to say her goodbyes to her father. He is her father, after all.

When the nurse talks about the daughter not being Bruno's legal representative, she again draws on the legal repertoire. When someone is assigned power of attorney, they are given all rights regarding access to medical information. When following the acute care path guided by the curing repertoire, information about the treatments and patient's condition can only be disclosed to the POA. However, now that Bruno has been extubated and is on the palliative care path, the nurse draws on the care repertoire to justify contacting the daughter, since dying alone is perceived as another kind of suffering and opposes the goal of making patients comfortable at the end of their lives. Indeed, calling the daughter at this moment becomes a necessary possible action within the care repertoire. The daughter arrived with her son

half an hour after she was called. Bruno was transferred that night to ensure that he would finally be allowed to die without re-entering the acute care path.

### ***Henry: Allowing Time to Heal***

The healthcare team invited me to Henry's family meeting, a second time that week, while he was still mechanically ventilated and in the ICU. The ICU doctor explained the various possibilities of Henry's trajectory:

MDICU2: Currently, since your father is not a DNR, if he improves, everything is fine. He will eventually be transferred to the ward and then back to the nursing home. However, if he does not improve and we are unable to extubate him, we will need to perform a tracheostomy in seven days. The surgery...is not very complex. However, if you choose this option, he will never be transferred to the ward and will remain in intensive care or [transferred to] a specialized long-term ventilator hospital. If this is what you want for your father's end-of-life care, this is what I'll do. But, to be honest, if he were a member of my family, this is not the option I would choose.

MDICU2 drew on different repertoires to help the family make decisions. The first two options he proposes align with the curing repertoire: Henry either improves enough to be taken off the ventilator and returned to the nursing home, or he will be extubated and given a tracheostomy. This surgery is usually done after patients have been on the ventilator for two weeks to avoid infection from the endotracheal tube; with a tracheostomy, the ventilator tube can be inserted directly into the trachea instead of via the mouth. However, the physician does not recommend the latter option.

The meeting continues:

HSON1: Is there another possible scenario?

MDICU2: Yes, but we need to change your father's status to DNR. If in seven days he does not improve, we could make him comfortable and let him pass away. We would stop all treatments and give him medication to ensure he is comfortable and doesn't suffer.

HSON2: So, if we agree to the DNR, we will not do the tracheostomy?

MDICU2: Yes, you're correct.

MDICU2 draws on the care repertoire when he proposes the third option, putting Henry back onto a palliative care path where his pain would be

managed and the ventilator would be withdrawn. However, as the physician implies when he says, “We need to change your father’s status to DNR,” there are legal requirements to go with the action possibilities of the care repertoire. Indeed, if the family agrees to sign a DNR, all the legal requirements will have been met that would align the care repertoire with the palliative path. But if the family disagrees, healthcare professionals must stay within the action possibilities available in the curing repertoire; most likely, the tracheostomy surgery would be performed. However, Henry’s third son proposes another possibility:

HSO<sub>N3</sub>: I think we should remove everything right away. Dad is a very sensitive person, and I’m certain he doesn’t like the sensation of the tube in his mouth. He had already signed the DNR before. He is in his room crying. We shouldn’t have put the tube in. We should remove everything immediately.

MDICU<sub>2</sub>: Removing the tube now isn’t a good idea. He’s very close to being extubated, but not today. I have no problem giving him the necessary treatments now if his condition doesn’t deteriorate. I just want to ensure that after treating him for this event, if another event occurs, we will not intubate him again.

HSO<sub>N1</sub>: So, to be clear, we are giving him aggressive treatments right now to help him improve. In the next seven days, you will try to remove the tube. If the tube needs to be reinserted, we will stop treatments and keep him comfortable.

MDICU<sub>2</sub>: That’s what I recommend, but it’s your decision.

The conversation ended with a show of hands. Three out of Henry’s four children wanted to continue the ventilator treatment for now, but they refused to have a tracheostomy. Only one wanted to stop the treatment and extubate. Henry was forced to continue the acute care path until he might be considered well enough for extubation.

Once the acute care path is chosen, the only way out of it using all repertoires is if the patient’s condition improves or if death occurs despite life-sustaining treatment. However, if there is a chance of curing the condition that rendered the use of the ventilator a possibility, then all repertoires will point towards continuing the treatment. Even if the family suggests withdrawing care, as Henry’s third son did, medical professionals will usually dismiss this request.

## Discussion

Other scholars have reported entanglements between the curing and caring repertoires, which Mol (2008 -ADD REF IN BIBLIO) solved by merging them together. That solution works when general medical decision-making is involved, since most of the time, each repertoire aligns with and directs actions toward the same possibilities. However, this can't be done to understand how end-of-life decisions are being taken, as the two logics operate very differently and provide for very different possibilities. Others have differentiated healing from curing (Hutchinson, Hutchinson, and Arnaert 2009; Kearney 2004). Their sense of the latter concept is the same as I have suggested here, in that curing refers to “action carried out by the health care practitioner to eradicate disease or correct a problem” (Hutchinson, Hutchinson, and Arnaert 2009, 835). Curing is epistemologically grounded in scientific knowledge, meaning that cause and effect relationships are investigated to control disease and ensure the survival of the biological body as the top priority while healing is “a process leading to a greater sense of integrity and wholeness in response to an injury or disease that occurs within the patient” (Hutchinson, Hutchinson, and Arnaert 2009, 835). These scholars added the term “healing” to give nuance to “curing,” but since these two terms are synonymous in common language, I adopted the term “care” or “caring” to emphasize the importance of the wholeness of the individual and relationships with other humans (Kearney 2004). The main aim of caring is to support optimal quality of life—even at the end of life (Prendergast and Puntillo 2002).

Although healthcare professionals would like to provide good care to elderly patients, sometimes they are restrained by legal repertoires. Indeed, as seen above, the legal repertoire guided most of the decisions about withholding, providing, or withdrawing life support treatment (that is, mechanical ventilation via endotracheal intubation). The transition from palliative care to acute care paths was mostly legitimized by the legalities of end-of-life care. Since this research was conducted in Ontario, Canada, the legislation that was operationalized throughout the two case studies was the Criminal Code of Canada and the Ontario Health Care Consent Act of 1996, reinforced by the Rasouli case law of 2013. According to the Criminal Code of Canada, providing the necessities to sustain life and inaction is considered a kind of action, so “letting nature” take its course, as some of the individuals on Bruno's and Henry's care teams advised, can constitute reckless or willful disregard for life (Downie 2016, 17). Allowing someone to die is considered criminal negligence under

section 220, and people who permit that can be charged with homicide under section 222 (Ibid.). The Criminal Code of Canada has existed since 1892 (Néron 1992, 652). Although it has been amended several times—including section 241(b), which now allows for medical aid in dying—certain sections still reflect Canadian values and possibilities for action from 1892, when mechanical ventilation did not yet exist. The Criminal Code still ensures that healthcare professionals will attempt every life-saving measure on all individuals who are not known to have a DNR or DNI. The national Criminal Code is supported by the provincial Ontario Health Care Consent Act of 1996, which gives healthcare professionals the right to provide treatment without consent when they believe death is imminent. Put together, these two pieces of legislation result in situations like Bruno’s, where he was intubated despite his POA having signed a DNR/DNI, occurring more often than one would expect, though little research has been done to demonstrate how often this happens (Silveira 2016). Before the Rasouli case, ER doctors would have corrected the mistake by simply removing the tube, as Silveira (2016) has described. However, the Rasouli case law of 2013 made a clear distinction between withholding and withdrawing treatment, and consent was needed for either action. Even if there was an order to withhold treatment, and treatment was accidentally administered, new consent would have to be obtained to withdraw treatment (Downie 2016). However, as was described for Henry’s situation, when medical professionals start life support treatment such as mechanical ventilation, they view it as having begun the curing process as part of the acute care path, and don’t feel comfortable withdrawing treatment at that point. Kaufman (2005) identified this moment as “the zone of indistinction,” wherein patients are stuck between life and death, healthcare professionals keep providing aggressive treatment, and families are unsure how to proceed. Even if these kinds of laws are mostly applied locally and differ between province and between countries, even at different medical institutions that are in the United States (the location of Kaufman’s research), they seem to produce the same outcomes, where patients remain on the acute care path and cannot leave it unless their condition significantly worsens or they temporarily get well enough to be extubated and transferred out of the ICU. This situation burdens healthcare professionals and family members alike.

In both case studies presented here, healthcare professionals confronted a moral dilemma around providing good end-of-life care. Such dilemmas can lead to moral distress or moral injury if they persist (Ritchie, et al. 2023; et al. 2015). Moral distress arises when a practitioner is certain they know the morally correct course of action but are unable to act upon it (Trotochaud et al., 2015).

This often happens when professionals know that death is inevitable, but life-sustaining measures are continued (Palma, et al. 2022; Orr, et al. 2022). Their moral distress is aggravated when they know what the patient wanted, but their patients' wishes are not respected. In such circumstances, not withdrawing care or inaction becomes more stressful than withdrawing care (Bruce, Miller, and Zimmerman 2015; Houston, et al. 2013). In both Bruno's and Henry's cases, healthcare professionals were bound by legalities that prevented them from offering appropriate palliative care.

Such legalities also put families in impossible situations, since the burden of decision often falls on them (Chartrand 2018). Bruno's son was the only one of his children with POA, which made it his individual responsibility to make end-of-life decisions on behalf of his father. Although Bruno had two children, assigning POA to only one inevitably imposed a hierarchy such that the opinion of one child was silenced by the decision of the other. By contrast, Henry assigned POA to all four of his children, so the burden of the decision to withdraw treatment was divided among the four of them in a more democratic process (Chartrand 2018). However, since the POA was distributed equally amongst all his children, any one of them can make a decision without everyone being present. This is what happened his one of his sons interpreted the "death rattle" as a sign of suffering and insisted on Henry being intubated, which put him back on the acute care path even though he had signed a DNR/DNI. This sort of transition from palliative to acute care happens often because members of the public seldom witness someone dying, and most social or media representations of "letting nature take its course" following extubation make it look and sound easy, with the breath gradually slowing until the heartbeat stops (Chartrand, 2020). Finally, as also seen in Henry's case, while the burden is shared in the collective decision-making model, that does not guarantee that everyone will be happy with the final decisions. (For further discussion of the difference between the collective and individualistic medical decision-making models, see Chartrand 2018.)

Since this study occurred during six months of fieldwork in one hospital in Ontario, Canada, my results only reflect what I observed among the 15 ventilated patients during that time. I am aware of other repertoires that could have guided end-of-life decisions and possibilities for action, but these were not captured in my research. For example, as seen in the Rasouli court case, religion provides guidance on what actions are possible, so the religious repertoire is probably being operationalized in acute and palliative care contexts. Although less often deployed in Canada because of its public healthcare system, the economic or

resource repertoires are also known to exist. For example, families that cannot afford to have their elderly relative treated in an ICU may keep them home or, as occurred during the COVID-19 pandemic, a lack of resources may block some patients from getting access to specialized medical technology, which also constrains the possibilities for action.

## **Conclusion**

By examining the interplay of legal, care, and curing repertoires during end-of-life decision-making in Ontario, Canada, this article has illuminated how palliative and acute care paths intersect or become intermittent, especially during critical moments of intubation and extubation. Healthcare professionals and patients' families continually renegotiate what it means to put patients on either path, leading to unpredictable care practices. Both Bruno and Henry were on the palliative path but oscillated back to acute care before returning to palliative care. The conversations among care teams during these transitions underscore the dynamism of end-of-life care, where legal, ethical, and emotional factors often conflict.

Legal considerations heavily influence end-of-life decisions, placing substantial burdens on healthcare providers and patients' families. Healthcare professionals must navigate legal requirements, honour the patient's and family's wishes, and face the moral dilemma of whether to "cure" or "care" for patients believed to be at the end of their lives. This can result in moral distress or injury. Families are thrust into difficult positions, whether one individual has POA (as in Bruno's case) or several do (as in Henry's case), complicating the decision-making process.

The primacy of the legal repertoire in decision-making can lead to patients becoming entrenched in acute care at the end of their lives, remaining in an indistinct liminal zone of neither living nor completely dying. This strains healthcare resources and pressures families and providers. Future research should quantify these liminal situations' prevalence and explore additional repertoires (for example, religious, economic) impacting decision-making. Comprehensive policy adjustments could then be developed to better support families and medical teams navigating complex, emotionally charged end-of-life decisions.

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## Notes

I Mr. Hassan Rasouli, a retired engineer, suffered severe brain damage after complications from surgery in 2010 at Sunnybrook Hospital in Toronto. His physicians concluded that he was in a permanent vegetative state and recommended the withdrawal of life support, including mechanical ventilation, on the grounds that further treatment was futile. His wife, Dr. Parichehr Salasel, herself a physician, disagreed and insisted that life support be continued, believing there were signs of responsiveness and that withdrawing treatment would be contrary to his values. In 2011, the Ontario Superior Court ruled in favour of Mrs. Rasouli, deciding that consent was legally required before doctors could withdraw life support. The case eventually reached the Supreme Court of Canada (2013), which upheld that ruling, confirming that withdrawal of life-sustaining treatment counts as a “treatment decision” under the law (Sibbald, Chidwick, and Hawryluck 2014).

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