

Article

# Individualism and the Decision to Withdraw Life Support

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**Abstract:** The 1996 Health Care Consent Act of Ontario (Canada) is a law that regulates medical decision making. Therefore, it also gives indications on how end of life decisions should be made. The goal of the law was to ensure and protect patient's autonomy and avoid medical paternalism, especially at the end of life. Throughout this article, I would like to argue that one of the consequences of the 1996 Health Care Consent Act of Ontario is to promote individualism. Therefore, this law makes it improbable to attain a shared decision model. More specifically, the way the 1996 Health Care Consent Act is currently written, a proxy is assigned as a decision-maker for someone who is deemed incompetent. However, it also ensures that the proxy will be the only one with the burden of that decision. This argument will be supported by providing a qualitative description of three cases that I have encountered during my six-month fieldwork in the Intensive Care Unit (ICU) of a hospital located in Ontario. This paper offers a reflection upon the consequences of using an alternative decision maker (proxy) to withdraw life support.

**Keywords:** end-of-life; autonomy; individualism; decision making; treatment withdraw; the 1996 Health Care Consent Act of Ontario; hospital ethnography; qualitative research

## 1. Introduction

The end of life is strongly shaped by societal values and changes over time and space [1]. Concentrating on western society, in *The Hour of Our Death*, Philippe Ariès (1977) describes the transition over two millennia upon societal values and its impact on the attitude about death [2]. As per Ariès (1977), death in the twentieth century is described as death denied. This type of attitude towards death was linked to the combination of secularization and the importance put towards medicalization. It was characterized by applied medical technology and omission of information by physicians. Also known as the paternalistic approach to medical care, it was considered to be the best way of protecting people from the anxiety of their own death.

Since then, many things have changed in regard to the way death and end of life is being handled. Indeed, palliative care has been introduced, combined with strong neoliberal values and their operationalization in law. First, palliative care is defined as “the study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life” [3] (p. 74). This new way of handling human sickness takes into consideration the fact that all humans are mortal, and that death is a part of the natural cycle of life [4]. The aim is to help families and individuals to relieve their pain during the process of the end of life. However, palliative care is not available to everyone for numerous reasons [1] (p. 18). Some still blame death denial among family members and patients [5] (pp. 299–302). More specifically, they identify death denial as being one of the major obstacles that prevents patients from seeking palliative care. Others argue it is the physicians that have difficulty having an open communication with families and patients who are at the end of life [6]. Another difficulty is that death remains highly unpredictable.

Palliative care helps those suffering from cancer where death can be foreseeable. In those instances, patients can make their own decision about their own way of dying. However, for those who have a chronic diagnosis, such as dementia or chronic heart failure, or have an acute event, such as a myocardial infarction, an embolus or a car accident, the event and timing of the dying process is highly uncertain and unpredictable. Often, treatment and life-saving measures are being used until death. Other times, the inevitability of death is predicted and now the question turns into how this should be handled. Should therapy and life support be withdrawn? In those types of circumstances, who should take the decision and who should be involved in this process? Who is the best person to know and who will respect and execute patient wishes?

Second, societal values have changed since the time of Aries. Even though neoliberal values were on the rise at that time, it is only a decade later that they have become operationalized within the laws of a nation. Now, “when a patient refuses medical treatment (withdrawing therapy), the law in Canada, UK, US requires that their stated wishes be respected unless they can be shown not to be legally competent” [7] (415). When shown not to be legally competent, for example when a patient is unconscious, the same countries have laws to help identify the patient’s legally authorized guardian or proxy. However, the laws can vary depending on the specific regions within the same country. Indeed, in the US each state has various jurisdiction. In the UK, in Scotland, it is the act of 2000, whereas in England and Wales it is the Mental Capacity Act 2005 [8]. Finally, in Canada, every province has their own sets of laws and regulations. More particularly, the law that I will be referring to throughout this paper took effect in 1996<sup>1</sup>: the 1996 Health Care Consent Act of Ontario. Many studies have shown the benefits of this kind of initiative, such as helping patient and family to be empowered [9] or to gain the sensation that they had a “good” death [10]. I am not going to argue the beneficial effects that this type of law may have in some circumstances. Many researchers have addressed the difficulty surrounding the concept of consent and how informed consent is never really well informed [11,12]. However, this is not the goal of this paper. Instead, I am going to argue that there are consequences that underlie the process of having to obtain consent and having to provide consent in the name of another person. More particularly, I am going to argue that in some circumstances, the law that should operationalize autonomy through consent actually puts more people in a heteronomous position and puts a tremendous burden on the person that is designated to decide. Therefore, it operationalizes individualism and becomes one of the contributing factors that divides families and friends at the death bed. Before explaining my qualitative research, I will explain the differences between autonomy and individualism, and the particular legal context within which the research has been done.

## 2. Key Concepts and Methods

### 2.1. *Autonomy vs. Individualism*

Many authors have used both terms interchangeably to essentially describe so-called western values [13,14]. These two concepts have also been used interchangeably to describe and frame how decisions about health and illness have been made [15]. For this paper, I find it important that those two concepts be explained separately. Autonomy, as it relates to an autonomous person, is defined as “when his or her behaviour is experienced as willingly enacted and when he or she fully endorses the actions in which he or she is engaged, and/or the values expressed by them” [16] (p. 98). Therefore, a decision of an autonomous person should truly reflect their interests, desires, and values [17]. The opposite of autonomy is heteronomy, and not dependence or collectiveness [16] (p. 98). Therefore,

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<sup>1</sup> Health Care in Canada is legislated at both the national and provincial level. At the national level, the Criminal Code and the Charter of Human Rights prevails over provincial laws. Each of the 10 provinces has specific laws that governs health care. Since my research was conducted in the province of Ontario, it is Ontario law that governs medical decisions that is going to be discussed; specifically, the 1996 Health Care Consent Act. This Act has been briefly amended since 1996 to clarify some of the wording, however, the specific section we discuss here has not been changed since it took effect.

autonomy should not be taken as the synonym of individualism. Heteronomy is when an individual's behaviour is forced upon the person, and which does not coincide with or reflect their interests, desires, and values. In making a decision, a person can remain autonomous while mutually depending on others (shared decision-making) or not (informed or individual decision-making).

Shared decision-making has been highly valorized by medical professionals. It is described as having four characteristics [18] (p. 80). First, it involves both medical professionals<sup>2</sup>, and patient and family, within the decision-making process. Second, both parties need to share information about each other. This allows for the two parties to know each other's positioning. Third, both parties will express their preferences and their reasoning for their preferences. Finally, both will come to an agreement [18] (p. 80). The opposite of shared decision-making is an individualistic model, also known as informed decision making<sup>3</sup>, which can be described by the following five characteristics. First, the doctor discusses the issues and the nature of the decision that needs to be made. Second, the doctor presents the alternatives, including their pros and cons, of the various choices that need to be made. Third, there is a question period during which some of the uncertainties can be addressed. Fourth, the doctor assesses the understanding of the patient or proxy to ensure that the level of comprehension is sufficient. Finally, the patient or proxy expresses their decision and the doctor follows exactly what has been expressed [18]. The big distinction lies in who makes the decision: who is accountable, and who accepts the responsibility for making the decision. In shared decision-making, many people are involved; the "who" is multiple<sup>4</sup> and takes the form of a group or a collective. The responsibility for making the decision is shared. In individual decision-making, the who is clearly identifiable and comes down to one person. The responsibility for making the decision is one person. Since consent is being operationalized in the written format, the responsibility for making the decision is directly linked to the person who has the responsibility of signing the consent. "Our signature can prompt such commitment and compliance because it is a powerful symbolic representation of the self" [22] (p. 84). Therefore, even if many people are consulted or provide their opinions, the person who signs has the full symbolic representation of the responsibility of the decision. Even though shared decision-making has been favoured over individualistic decision-making in the medical field [9], the laws that are presently in place to protect patients' autonomy make it impossible to fully allow shared decision-making<sup>5</sup> since only one person's signature is needed to attest for consent.

## 2.2. Legal Context for Medical Decision-Making: The 1996 Health Care Consent Act of Ontario, Canada

To promote autonomy in end of life decisions, patients' directives and wishes to withhold<sup>6</sup> therapy has been widely accepted in Canada since 1984 [26]. However, it was not until 1996, following the Nancy B court case in Quebec, that autonomy was integrated and formalized within law, and also promoted for treatment withdrawal<sup>7</sup>. In 1993, Nancy B, a woman with Guillain-Barré disease, requested the right to withdraw life support due to the autoimmune disease that caused Nancy B to be chronically ventilated. Her doctors would not withdraw life support on the basis that they did not want to be charged criminally for negligence or causing death [27]. As per Justice Dufour, the Criminal

<sup>2</sup> In the literature, the doctor is indicated and not medical professionals. Since I believe that true, shared decision-making should also involve other professionals such as nurses, respiratory therapists, physiotherapists and others, I prefer integrating every professional instead of limiting it to the doctor.

<sup>3</sup> This type of decision-making has also been argued to be the way of achieving autonomy. It has been largely criticized; for more information see [11,19,20]. I believe that it is this overlap between autonomy and informed decision that blurs the distinction between autonomy and individualism.

<sup>4</sup> More than one, fewer than many [21].

<sup>5</sup> In the literature, there has been some distinction between the various steps of the process of decision-making, and there has been some discussion about the decision-making continuum, where some decisions can involve a mixture of the individualistic model and shared decision-making [20,23–25]. In this paper I talk about the final decision to withdraw life support, and identify who makes the decision and the consequences of making that decision. More precisely, whose signature is needed in order to attest that consent has been obtained and that withdraw should proceed.

<sup>6</sup> A "do not resuscitate" order is an example of not starting a treatment that could potentially "save a life".

<sup>7</sup> To stop a treatment that has already been started that could potentially "save a life" or "maintain life".

Code and the Charter of Human Rights should be read together. Therefore, Justice Dufour concluded that we must respect personal choice and autonomy when it comes to the end of life. More specifically, patients should be given the right to decide to withdraw therapy, and health care professionals should not be held criminally responsible when treatment withdrawal is being requested by the patient or by the patient's proxy [27]. Following Justice Dufour's verdict, many provinces in Canada established a law to ensure that patient's autonomy would be respected by health care professionals. The Province of Ontario was one of those provinces, establishing the 1996 Health Care Consent Act. In general, the purpose of the Act is to enhance autonomy of a person, to promote communication between a medical professional and their patient and family, and to integrate supportive family members within the medical decision-making process<sup>8</sup>. The 1996 Health Care Consent Act also provides provision as to how to proceed when someone becomes incompetent. Per this Act, when a person is deemed incompetent, an alternative decision maker is assigned. The capacity to provide consent is transferred from one individual to another. More specifically, Section 20 of this Act highlights the criteria and the ranking of who should be providing consent for the incapable person<sup>9</sup>. The Act also indicates that if no-one fits those criteria, a public guardian should be assigned.

When a decision is being made about withdrawing treatment, two doctors have to agree and attest that withdrawal is the appropriate course of action, before having this discussion with the alternative decision maker. After making this observation, the doctor will present the various scenarios to the family or loved ones in order to get informed consent to withdraw treatment; the ventilator in the case that will be presented here. Let us now see how this is being articulated in practice.

### 2.3. The Research

The results provided in this article are a portion of my doctoral project during which I seek to understand the decision-making process surrounding the ventilator, more commonly known as the breathing machine or life support. Aside from being a simple technology that takes over the breathing function of a sick individual, the ventilator can be a lifesaving treatment or become an aggressive therapy that obstructs death with dignity. A portion of the results was also presented during the annual meeting of the Society for Applied Anthropology (SfAA) in 2017. The description provided here focuses on the consequences of the transfer of autonomy to an alternative decision maker, which is regulated, as previously mentioned, by the 1996 Health Care Consent Act of Ontario.

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<sup>8</sup> The exact statement of the Law states: The purpose of the Act is (a) to provide rules with respect to consent to treatment that apply consistently in all settings; (b) to facilitate treatment, admission to care facilities, and personal assistance services, for persons lacking the capacity to make decisions about such matters; (c) to enhance the autonomy of persons for whom treatment is proposed, persons for whom admission to a care facility is proposed and persons who are to receive personal assistance services by (i) allowing those who have been found to be incapable to apply to a tribunal for a review of the finding (ii) allowing incapable persons to request that a representative of their choice is appointed by the tribunal for the purpose of making decisions on their behalf concerning treatment, admission to a care facility or personal assistance services, and (iii) requiring that wishes with respect to treatment, admission to a care facility or personal assistance services, expressed by persons while capable and after attaining 16 years of age, be adhered to; (d) to promote communication and understanding between health practitioners and their patients or clients; (e) to ensure a significant role for supportive family members when a person lacks the capacity to make a decision about a treatment, admission to a care facility or a personal assistance service; and (f) to permit intervention by the Public Guardian and Trustee only as a last resort in decisions on behalf of incapable persons concerning treatment, admission to a care facility or personal assistance services.

<sup>9</sup> Section 20. (1) If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs: 1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment. 2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent to the treatment. 3. The incapable person's representative appointed by the Board under Section 3.3, if the representative has authority to give or refuse consent to the treatment. 4. The incapable person's spouse or partner. 5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent. 6. A parent of the incapable person who has only a right of access. 7. A brother or sister of the incapable person. 8. Any other relative of the incapable person.

### 2.3.1. Research Method

I have conducted ethnographic qualitative research during a six-month period in the Intensive Care Unit (ICU) of a hospital located in the province of Ontario, Canada. During my fieldwork, I adopted an interactive approach, where interviews were non-formal, often taking the shape of focus groups, and where active listening replaced participatory observation [28]. This method seemed to be the most beneficial for gathering information, since the ICU is a high-volume and high-stress location where staff and family members do not have time for formal interviews but always appreciate a five-minute chat. Overall, I undertook 705 h of observation, where 15 ventilated patients were followed during every step of the decision making. To achieve this, a total of 121 people were recruited and consulted while decisions were in process. Said differently, since events were changing rapidly and highly uncertain, this method allowed me to get reactions and insights of individuals that were involved while situations were unfolding. Finally, this provided me with the opportunity to discuss what was happening with various professionals and various family members in the moment that decisions were being made.

### 2.3.2. Researcher's Position

During the fieldwork, the position of researchers was maintained. However, I am a respiratory therapist that has been working in a hospital setting since 2001. This former role came as both an advantage and a disadvantage during my research. For instance, I know that my access to the ICU and the liberty I had in the unit was due to the trust I had already earned amongst my profession. However, some people confused a PhD student with respiratory students; as a result, I was sometimes asked by staff to perform respiratory therapist tasks, which I gently declined to do.

### 2.3.3. Ethical Consideration

I have received ethical approval from my academic institution<sup>10</sup> and the hospital, which preferred to stay anonymous. Consent of all participants was obtained either with a signed consent form or with verbal approval. All names and other identifiers, such as geographic regions, have been modified to respect anonymity. All other principles of ethics were and are still being respected.

## 3. In Practice: Withdrawing Life Support

In this section, I am going to provide the description of the decision to withdraw life support. The three following cases have a common element, in that at one point during their medical trajectories<sup>11</sup>, medical professionals and the family involved were, in consultation with each other, trying to decide if withdrawing life support was the best course of action. All three cases relate to individuals that were not capable of making their own decisions. Therefore, the individual's autonomy had to be transferred to an alternative decision maker. In two of the cases provided, the alternative decision maker was either chosen by the person prior to becoming ill or identified by default, using the list stated in the Act. In one of the cases, it was more difficult to find a person that fitted the criteria as an alternative decision maker, since the patient had no immediate family as defined by the Act. For all three descriptions, I am going to start with a summary of their respective situation, followed by responses to questions asked of those involved in the case about who was to make the decision and how they felt about the decision that had been made.

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<sup>10</sup> Case # H03-15-15 since approval of the University was conditional on approval of the hospital, the hospital remains anonymous as requested.

<sup>11</sup> Trajectory is a term coined by the authors to refer not only to the physiological unfolding of a patient's disease, but to the total organization of work done over its course, plus the impact on those involved with that work and its organization. For different illnesses, the trajectory will involve different medical and nursing actions, different kinds of skills and other resources, a different parcelling out of tasks among the workers (including, perhaps, kin and the patient), and involving quite different relationships—both instrumental and expressive—among the workers [21] (p. 8) [29].

### 3.1. Margarita

Margarita was a 72-year-old woman who had been diagnosed with end-stage dementia. Before being admitted to the ICU, she was living in a nursing home where she was considered to be active with severe progressive decline of her mental capacity<sup>12</sup>. Margarita was initially intubated due to pneumonia. After a week of being intubated (mechanical ventilation initiated) and treated for her infection, medical professionals attempted to extubate her. However, two hours after the first extubation (mechanical ventilation removed), Margarita had to be re-intubated because she was not breathing sufficiently. After numerous testing, the medical professionals concluded that Margarita would never be able to breathe on her own again. The main hypothesis was that dementia was so severe that it was suppressing her respiratory drive. This was a hypothesis, because no concrete testing could be done to support this with certainty. The only certainty was that a decision had to be made in regard to the treatment plan<sup>13</sup>. Doctors coming from the areas of palliative care and respirology both suggested that withdrawing<sup>1</sup> life support to “let nature take its course” was the best option for Margarita, but prior to this consent had to be obtained. Margarita had two children and two friends that came to visit her every day. Her daughter, who lived in Mexico, was in town to care for her mother since she had been hospitalized. Her son, who lives in the same city as Margarita, was legally appointed the alternative decision maker when Margarita had still been capable of making her own decision.

#### 3.1.1. Who Makes the Decision to Withdraw Life Support? How do You Feel about This?

*Son:* I know my mother will die eventually but being responsible for her death is impossible. The thing is, I must be able to live with myself after the decision. I love my mother dearly, I do not want her to suffer, but I can't live with knowing that I had anything to do with her death. We don't know. They are not even certain that it is because of the dementia that she is breathing this way. I know I have to come to terms with my mother's death and this is why I am consulting a psychiatrist. My mother is a fighter and since she fought for her life against cancer, I am choosing to fight for her life this time around. My sister can say anything she wants, but at the end of the day I am the one who must make that choice for my mother. I choose the tracheostomy, I choose life.

*Daughter:* It is my brother that makes the decision. I know him, it is not going to go well and he is going to push so that my mother has the tracheostomy. It is breaking my heart to see her this way. She keeps on pulling on everything, maybe that is her saying that she had enough. I know if I would be in this position, I would want people to let me die. This is not a quality of life, this is not a life. I am so sad. There is absolutely nothing I can do about it. In the end, it is my brother who is going to decide.

*Friend:* I am so upset at him. He is just selfish you know. He sees what he wants to see and, in the meantime, his life can continue undisturbed while his mother is here. He wants the tracheostomy, so his mother stays alive while he goes on vacation. I know Margarita. She has been my friend for over 20 years. She was a strong independent woman that loved to enjoy life. We travelled together often, and we had such an amazing time. I know that it is hard to see because she is smiling all the time, but this is because of her dementia I am sure she is suffering. Knowing her, she would have rather

<sup>12</sup> According to the dietician who was working at the nursing home, Margarita was always walking. However, this was seen more as a reflex than an action since she could not avoid any obstacles. Said differently, if she encountered a wall, she would back up and hit the wall over and over again till someone came to change her direction.

<sup>13</sup> Usually, because of increased chances of infection and chances of causing tracheal deformity, the endotracheal tube needs to be replaced with a tracheostomy. However, performing this kind of procedure on someone with severe dementia is highly contested in the medical literature.

<sup>1</sup> Health Care in Canada is legislated at both the national and provincial level. At the national level, the Criminal Code and the Charter of Human Rights prevails over provincial laws. Each of the 10 provinces has specific laws that governs health care. Since my research was conducted in the province of Ontario, it is Ontario law that governs medical decisions that is going to be discussed; specifically, the 1996 Health Care Consent Act. This Act has been briefly amended since 1996 to clarify some of the wording, however, the specific section we discuss here has not been changed since it took effect.

died than being given a bath by two men. She would have rather died than being stuck in that bed all day long. Suffering can be emotional, not just physical. I am sorry for ranting, one way or the other there is nothing I can do. I am just a friend and it is her son that is taking the decision.

*Doctor:* It is a difficult situation and the son must make an impossible decision but doing a tracheostomy on a patient with end-stage dementia is just cruel on so many levels.

### 3.1.2. Outcome

Margarita had the surgical procedure for the tracheostomy. Her daughter had to return home to take care of her family. She attempted numerous times to get information about her mother's condition. However, every time she called the medical professionals could not give information since she did not have power of attorney. Even though she tried to explain that her brother would not return her calls, they were insisting that she needed to call him. Two months after the surgical procedure, Margarita was still alive in her hospital bed. At that point, visitors, including her son, were coming in once every two weeks and only for an hour or two.

### 3.2. George

George was a 62-year-old man who was found unconscious on his kitchen floor by a friend. He was intubated for respiratory failure due to unknown causes, and later diagnosed with partial intestinal ischemia. He was immediately sent to the operating theatre for intestinal resection. He was slowly recovering in the ICU till his condition drastically changed on the second day following the procedure. A Computed Tomography (CT) scan confirmed total intestinal ischemia, for which nothing could be medically done to cure this condition. George was still on life support. A decision had to be made regarding withdrawal of treatment. Per the medical professionals, since his condition was irreversible, it was best to withdraw therapy. George had five friends who came to the hospital to visit him. However, even though George had appointed someone to be responsible for his financial affairs in the event he became incapable, he did not appoint a medical proxy. Furthermore, George was an only child who never married and did not have children. His parents had both passed away. His father was an only child and his mother had one brother who had one child. His mother's brother had passed away, but George kept in contact with his cousin (he saw him twice a year), who was living out of town.

#### 3.2.1. Who Makes the Decision to Withdraw Life Support? How do You Feel about This?

*Doctor:* I love dealing with friends instead of dealing with the family. They are much more reasonable than the family. See how it was easy when I spoke to them? All of them understood that it was the best way to go and that life support only extended his suffering. I am confident that his cousin will have the same reaction. I wish that those discussions would always be that easy.

*Friend 1:* I know George would not want to be in that condition. I know George for 35 years now. We met at work and we had always been close. I, friend 2 and him even called each other brothers and sisters. When we needed anything, we were there for each other. We were even there at his mother's death bed and helped him organize the funeral. He is going to join her now. I never thought it would be so soon. I wish this would not have happened, but it is the best way for him to go. We are all going to be here. He is not going to die alone. We all agreed to take the machine away and we all took the decision along with the doctors.

*Friend 3:* Miracle does happen. I really don't want him to die. What if the doctors are wrong? Maybe we are giving up on him too fast? But everybody seems to agree with the doctors that stopping treatment is the best way to go. I am going to miss him so much. I don't want him to go, I don't want him to die. Please don't die.

*Friend 4:* His mother had cancer and she suffered for many years. Every time George saw her, he always said that in her condition he would rather die. We are only respecting what he would have wanted us to do.

*Nurse:* I don't get life sometimes. We have done everything right with him and then this happens. I am happy that the suffering is not going to be extended with useless intervention. I am happy that at least everyone agrees but I am just confused as to what our role is in all of this. Why work so hard, when death is out of our control anyways?

### 3.2.2. Outcome

George passed away six hours after life support was discontinued. His friends stayed at his bedside during that whole time. They were exchanging stories about who George was when he was alive.

### 3.3. Mary

Mary was a 62-year-old woman who were found V.S.A.<sup>14</sup> on the street. Resuscitative measures were carried out at the scene and, following arrival at the hospital, her heart resumed beating. She was transferred to the ICU. Since medical professionals did not know how long it took for the initiation of resuscitative measures following her cardiac event, they had to wait to see whether her condition would improve. She had constant seizures that were indicative that her brain was severely affected. Five days following admission, her condition had not improved, and a decision had to be made. Mary was living with her boyfriend, making them subject to common law. She did not have any children and her parents had passed away several years ago. She had cousins that were living in eastern Canada, but who did not keep in touch with Mary.

#### 3.3.1. Who Makes the Decision to Withdraw Life Support? How do You Feel about This?

*Social worker:* Per the law, she is under common law and he [the boyfriend] is the one responsible for taking the decision. The boyfriend becomes the alternative decision maker. I think he just doesn't want to take the decision. Then again, he was dodging when she was admitted telling us he was her friend then her boyfriend and it's only by asking his address and phone number that I realized that they were living together. It is sad because during this time she is the one suffering.

*The resident:* I tried so hard to put the responsibility of the decision on my shoulder, do you agree? I made sure to tell him that it was our finding and that I strongly suggested withdrawing therapy. I really don't know how I could have made it so that he would not feel responsible.

*Boyfriend:* I understand that Mary is suffering and that she is going to pass away regardless if I choose or not to withdraw therapy. I agree that it would be best for her to withdraw treatment. I am afraid that her family, even if they have not spoken to each other for the last five years, is going to come back at me and accuse me of murdering her. I can't live to be scared all the time that I will be accused of murder. I don't think I should be responsible to take that decision.

### 3.3.2. Outcome

Mary passed away ten minutes before the scheduled meeting with her boyfriend to provide him with a letter from a lawyer indicating that he was the rightful alternative decision maker and that her family would not have grounds to accuse him of murder. When she arrested, medical professionals performed resuscitative measures since they did not have a valid order to indicate that they should do otherwise. However, the intervention was brief.

## 4. Discussion: Autonomy, or Should I Say Individualism?

As previously mentioned, the 1996 Health Care Consent Act of Ontario tries to promote patient autonomy. When a patient can state their wish, this Act ensures that the patient has a voice in

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<sup>14</sup> Vital signs absent (VSA)

decisions related to their own medical treatment. The decisions are usually not made alone. Usually the patient will consult with loved ones and medical professionals before stating their preferences. Furthermore, when they die, the consequences of having to make this decision die with them. However, when patients lose capacity, the Act ensures that someone from the patient's family or based on the patient's choice can make the decision rather than a medical professional. I see the same form of decision-making models as in the paternalistic model: that is, individualism. Indeed, in the paternalistic model, doctors acting as the autonomous individuals and patients as the heteronomous ones. Doctors were making the decisions alone without consulting patients. Under the Act, it is a proxy, rather than a doctor, that is acting as such. Even though this decision can be made in consultation with others, only one person is assigned to sign the consent form.

When a proxy is assigned, the capacity to provide consent is transferred from one person to the other. In the transfer of consent, autonomy also becomes individualism. Because of the Act, even if healthcare professionals believe that the right course of action is to withdraw life support, if the proxy decides otherwise the healthcare professional are bound to continue treatment.<sup>15</sup> As can be seen with Margarita and Mary, the alternative decision maker did not decide that withdrawing therapy was the best course of action. Even if the medical professionals involved carefully assessed the diagnosis to ensure that death was indeed inevitable and foreseeable, it was the alternative decision maker that had the final word. If they were to consent to withdraw therapy, they had to provide their signature as a testament of consent yet by doing this they were also taken on the burden of the decision to withdraw therapy. The alternative decision makers for both Margarita and Mary had to sign forms to approve withdraw of therapy. There were no questions as to who was making the decision: they were. Both Mary's and Margarita's proxies stated that they felt that by signing consent, they were contributing to the death of their loved ones. Even though withdrawing therapy is not considered as a contribution to death but, rather, "letting nature take its course," it is not uncommon for the person who signs a consent form to perceive withdrawing life support as such [28,30,31]. Therefore, it is not surprising to see both alternative decision makers refusing to sign the consent form.

In Mary's situation, her alternative decision maker did not even want to be identified as the person making the decision. During the meeting, he always brought another person with him and asked for that person's advice about the situation. However, he was the one who had to sign consent. In this situation, the law that tries to promote autonomy achieves the opposite: the decision is being imposed on the individual. In Margarita's situation, her son was an autonomous individual and accepted this responsibility. However, in doing so, he also put his mother's friend, his sister, and the medical professionals in a heteronomous situation. Even though he was not consulting with his sister or his mother's friend, he was asking for advice from his wife. However, he was the one who had to sign consent. In these two cases, many people were involved. However, the responsibility and the burden of the decision fell on one person. The choice of life, or not choosing, was preferred over the one to withdraw therapy. Contrary to when the patient is able to take the decision, the proxy will have to live with the consequences of their decision to withdraw life support. Dying versus living with the decision ensures that the burden of decision is heavier on the survivor.

When no legal proxy is available or able to be clearly identified, autonomy is transferred to a collective. It becomes difficult to identify who is responsible for the decision, because everybody is. As we saw with George, the doctors believed they had obtained consent by his social circle and his social circle believed that the doctors were making the decisions. His social circle also believed that everybody was involved in the decision. The burden was also shared between everyone that was involved in this process. Therefore, when autonomy is transferred to a collective it can also become shared decision-making. Since a single doctor cannot decide to discontinue life support on their own, they need to ask others to agree with his findings. Furthermore, since the law requires

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<sup>15</sup> See Rasouli case: <https://scc-csc.lexum.com/scc-csc/scc-csc/fr/item/13290/index.do>.

that consent be given by a patient representative, the social circle was consulted. Since the majority agreed and that there were no one that radically objected to withdrawing life support, a legal guardian was not necessary. In fact, the legal guardian became a collective: George's social circle. Therefore, the burden of decision is now shared between a collective of both medical professionals and the patient's social circle. Although the survivors will live with this decision, the burden is also shared by many. The choice of removing life support sooner rather than later was preferred over continuing with life-saving measures.

## 5. Conclusions

The cases presented here are local. Indeed, they come from one hospital located in the province of Ontario that happened in 2015. The research is also specific, since it discusses the implication of the law when deciding for another person about the ventilator. Therefore, the research does have limitations, since it does not address other factors, such as religion, in the implications for this kind of decision. However, the cases are also echoed in other research that has been carried out in different countries at other times [6,31,32]. Therefore, the cases are also representative of the problems associated with death in modern society. Since death denial has been pointed out to be a problematic way of dealing with death in modern society, a lot has been done to try to improve the quality of the dying. However, as I have described here, there are still many controversies, and many people who suffer from the ways of handling end of life.

One of the latest initiatives to improve treatment withdrawal in Canada was undertaken in the province of Quebec. Indeed, an act respecting end-of-life care was passed on 5 June 2014 and came into force in December 2015. This act allows individuals to express their wishes in advance. The form provides various scenarios in which an individual can identify their consent so that the responsibility of the decision is taken by the individual concerned. Therefore, this directive by anticipation takes precedence over a proxy's decision. The hope of this law is that a proxy would not be responsible for the decision. The main issue identified with this type of initiative is that it does not take in consideration that fact that a person might change their mind depending on the context and the situation. There is a big gap between what people might think they want if a situation happens versus what people really chose during a situation. More concretely, during the time of my fieldwork, I have seen family members override a Do Not Resuscitate Order (DNR) order that has been signed by the patient. They did this, not because of disrespect towards their loved one's wishes, but because at that time they felt their loved one was suffering, and something should be done to relieve the suffering, even if this meant they had to initiate the ventilator. There is still a lot that is unknown and that needs to be further investigated.

I would like to finish by proposing to steer the reflection in another direction. I would like to make a proposal following the actions of George's social circle. More particularly, I propose that some of the answers to this sort of issue rely on the same ideal that brought us here in the first place: democracy. Neoliberal values have at their foundation the idea that every opinion is important and must be heard. The way of operationalizing democracy was to create a voting system where everyone has the right to vote, and in which everyone should have a voice unless they willingly decide to refrain from voting. The decision is then made by the choice of the majority—the collective. This is what happened in the case of George's decision: everyone had a voice and the choice was one made by the majority. This ensures that every person's autonomy is being respected and that the decision is based on shared values. Furthermore, this way the burden of the responsibility of choice is also shared. If democracy is being used to make important decisions, such as choosing who is going to run the country, why do we not use it to decide for individuals who can no longer provide their consent? This way, not just the voice of one family member could be heard; every single family member, and even friends, could have an impact on the decision. This is also true about medical professionals, where too often the doctors are identified as the decision maker. A democratic decision about withdrawal of treatment would also include nurses, respiratory therapists, and other allied health care workers, who are directly involved

in the care of a patient. If dying with dignity is dying with autonomy, let us make our decision-making process more collective. Let us aim for a democratic withdrawal.

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