

“Can’t you at least die with a little dignity?” The Right to Die Debates and Normative Dignity

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Résumé

Au cours des dernières décennies, le droit de mourir a émergé comme l’une des questions sociales et politiques les plus controversées en Amérique du Nord et en Europe. Celui-ci implique la mobilisation de nombreux acteurs sociaux et militants ainsi que plusieurs défis juridiques. Au Québec, le législateur provincial a formé le « Comité spécial sur la question de mourir dans la dignité », un groupe de législateurs chargé d’examiner la question. Dans leur rapport de 2012, ils recommandent la légalisation de « l’aide médicale à mourir » comme une partie appropriée de la continuité des soins de fin de vie. À partir d’une méta-analyse des observations écrites et orales recueillies par le Comité dans différents endroits de la province, cet article présente plusieurs significations concurrentes de ce que signifie la dignité humaine à la fin de la vie. Les définitions intrinsèques de la dignité – qu’elles soient religieuses ou philosophiques – associent souvent la dignité à une acceptation de la mort. Ces définitions sont en concurrence avec une compréhension plus relative et contingente de la dignité. Dans une telle perspective, la dignité dépend de l’état physique ou mental de l’individu. Ici, « mourir avec dignité » signifie mourir sans souffrances indues ou en perte d’autonomie. Que « mourir avec dignité » est défini comme étant une mort paisible ou significative ou bien comme une fin de vie sans souffrances indues ou sans perte d’autonomie. Ces appellations normatives tiennent toutes pour acquis que les êtres humains veulent mourir dans la dignité. Cet article analyse les multiples significations de la dignité dans le débat concernant le droit de mourir tout en contestant l’hypothèse qu’une « bonne mort » est nécessairement synonyme de « mourir dans la dignité ».

Mots clés

débat sur le droit de mourir, Québec, dignité intrinsèque, dignité relative, bonne mort, euthanasie, normativité

Abstract

In recent decades, the right to die has emerged as one of the most divisive social and political questions in North America and Europe, one that involves the mobilization of numerous social actors and activists as well as several legal challenges. In Québec, the provincial legislature formed the “Select Committee on Dying with Dignity”, a group of legislators tasked with examining the issue. In their 2012 report, they recommend the legalization of “medical aid in dying” as an appropriate part of the continuum of care at the end of life. From a meta-analysis of the written and oral submissions collected by the Committee in different locations throughout the province, this article presents several competing meanings of what human dignity means at the end of life. Intrinsic definitions of dignity – whether religious or philosophical – often associate dignity with an acceptance of death. These definitions of dignity compete with more relative and contingent understandings of dignity. In such a view, dignity depends on the physical or mental condition of the individual. Here “dying with dignity” means dying without undue suffering or loss of autonomy. Whether “dying with dignity” is defined as having a peaceful or meaningful death or alternatively as an end-of-life without undue suffering or loss of autonomy, these normative calls all take for granted that human beings want to die with dignity. This article analyzes the multiple meanings of dignity in the right to die debate while challenging the assumption that a “good death” is necessary synonymous with “dying with dignity.”

Keywords

right to die debate, Québec, intrinsic dignity, relative dignity, good death, euthanasia, normativity

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Introduction

During the 2012 French presidential election, the *Association pour le droit de mourir dans la dignité* (Association for the Right to Die with Dignity) launched a controversial campaign featuring photo-shopped images of French president Nicolas Sarkozy and other candidates opposed to euthanasia as dying patients alone in hospital beds and hooked up to machines in an effort to convince them to change their opinions on the issue. The caption: "Must you be put in this position to change your stance on euthanasia?" The campaign is based on an empathic appeal. The underlying premise: if they were suffering an agonizing dying process, they would support the right to die. In other words, anybody dying under such "undignified" conditions should favour the cause.

In recent decades, the right to die has emerged as one of the most divisive social and political questions in North America and Europe, one that involves the mobilization of numerous social actors and activists as well as several legal challenges [1]. In Québec, the provincial legislature formed a "Select Committee on Dying with Dignity." In its 2012 report, the committee recommended the legalization of "medical aid in dying" [2]. The committee's name highlights the centrality of the concept of dignity in such discussions [3]. This centrality is also evident in the name of Québec's most prominent right-to-die organization, the *Association québécoise pour le droit de mourir dans la dignité* (Québec Association for the Right to Die with Dignity). At the same time, the anti-euthanasia movement uses the language of dignity as well, such as the Québec anti-euthanasia organization called *Vivre dans la Dignité* (Living With Dignity).

The question arises: Why has dignity become the defining and unifying aspect of the right to die debates? This paper attempts to answer this question by examining how dignity is employed in practice by the various actors involved in the right to die debate. Focused primarily on the Québec context, the aim is to understand the diverse ways different social activists engage with the concept. This discussion may be termed 'dignity talk', in reference to the work of anthropologist Frances Norwood [4]. In attempting to understand why euthanasia and assisted suicide was readily available in the Netherlands but rarely employed, Norwood coined the term 'euthanasia talk' to express how euthanasia provides a discourse for framing end-of-life discussions in the Netherlands. Before analyzing the Select Committee testimonies in an exploratory manner, this paper will first present the legal situation in Canada and then briefly discuss the relationship between human rights and dignity before moving to a discussion of the use of dignity in right to die debates.

Whether “Dying with dignity” is defined as having a meaningful death (as proposed for instance by Dignity Therapy) or as a death without undue suffering or loss of autonomy (as proposed by the right to die movement), “dying with dignity” is now synonymous with having “a good death.” Thus, dignity appears to provide a unifying and normative vocabulary for the debate but, as we will show, because of its disparate and contested meanings, when various actors invoke dignity they are speaking about differing, even contradictory, underlying ideals based on opposing conceptions of the term. Moreover, dignity represents a taken for granted ideal of both sides of the debate, with an assumption that all human beings desire to die with dignity. Why do actors involved in the right to die debates argue in terms of dignity? What are the various actors talking about when discussing the meaning of dignity? This article will attempt to answer these questions while problematizing this assumption of a “normative dignity.”

Legal Situation in Canada

In the vast majority of Western countries, euthanasia (the intentional killing of another person in order to relieve their suffering) and assisted suicide (the act of killing oneself with assistance from others) are illegal. Countries that permit these practices include The Netherlands, Luxembourg (authorizing both euthanasia and assisted suicide), Belgium (only euthanasia), Switzerland and a handful of US States such as Oregon, Washington, Montana, and Vermont (only assisted suicide). In Canada, although suicide and attempted suicide were decriminalized in 1972, assisted suicide remains a prosecutable criminal act. Euthanasia, however, is not defined in the Criminal Code and does not have legal standing. To date, it has been treated as first- or second-degree murder. In 1992, the Supreme Court decided by a single vote margin to refuse Sue Rodriguez, a woman with advanced Amyotrophic Lateral Sclerosis (ALS), the right to die. Several private members’ bills attempting to legalize assisted suicide have been subsequently defeated in Parliament, including most recently Bill-C-384 in 2010 [1]. However, Canadian law currently faces two challenges, one in British Columbia and one in Québec, both revealing tensions between the Federal Government and provinces regarding jurisdiction over this issue. In June 2012, a Supreme Court judge in British Columbia struck down laws banning assisted suicide, and the ruling was suspended to allow parliament time to draft new legislation. The plaintiff in the case – Gloria Taylor – was given an individual exemption, but died of natural causes in October 2012. A year later, the British Columbia Court of Appeal overturned the ruling in a split decision. Some twenty years after the Sue Rodriguez’ case, this issue will be reconsidered by the Supreme Court of Canada.

Meanwhile, in Québec, according to most public opinion polls, a large majority of the population favours both euthanasia and assisted suicide, more so than any other Canadian provinces [5]. On December 5, 2009, the Québec National Assembly’s Health and Social Services Commission formed the “Select Committee on Dying with Dignity” to undertake a public consultation. Over the course of two years, the Committee solicited written briefs from expert witnesses, activists and other concerned citizens and organizations. It also prepared a consultation paper, solicited online questionnaires and held public hearings in eleven different locations throughout the province. Medical, religious, and academic perspectives were represented among others. In the end, more than 500 written and oral submissions from the public were received. The popularity of the hearings surpassed expectations, attracting record-breaking participation for a public consultation. In its 2012 report, the Select Committee recommended a general improvement in palliative care services as well as the recognition of “medical aid in dying”, an expression that, as the reports surprisingly states, “gradually emerged on its own” [2, p. 76]. In January 2013, an expert judicial panel appointed by the government of Québec confirmed the feasibility of the recommendations of the Select Committee [6]. A first reading of Bill 52 – authorizing “medical aid in dying” – took place in June 2013 and one year later, the Québec National Assembly officially approved Bill 52 by a vote of 94 to 22.

Dignity and Human Rights

As noted earlier, the concept of dignity is central to the debate in Québec. Indeed, it has emerged as a “nodal point” [7] insofar as it is the central concept around which different actors organize their arguments. Although dignity has been criticized in the literature for being an empty slogan, “a kind of woolly uplift” [8] and even a “useless” concept [9], its polysemic ability to engender contradictory and competing understandings is precisely what makes the term so productive. Historically, human dignity became linked to human rights in the 1948 United Nations Declaration of Human Rights [10]. The term ‘dignity’ appears in the first article – *All human beings are born free and equal in dignity and rights* – and has become so intertwined with human rights to the point that according to Dworkin, “the vague but powerful idea of human dignity” must be accepted by “anyone who professes to take rights seriously” [11, p. 198]. Human dignity is often understood as the justification [10] or the rationale behind rights: “Human dignity and human rights are therefore mutually dependent but in different ways. The relationship between them is that of a principle and the concrete legal norms that are needed to flesh out that principle in real life” [12, p. 234]. At the same time, in recent years the principle of respect for human dignity has played a key role in bioethics, including in international instruments regulating biomedical practices such as the 2005 UNESCO Universal Declaration on Bioethics and Human Rights and the 1997 Convention on Human Rights and Biomedicine adopted by the Council of Europe. In these understandings that stem from the Kantian tradition [13], dignity results from a distinctive intrinsic value that is unique to being human. Within this tradition, dignity is violated when humans are treated as means rather than ends [13, p. 77].

Intrinsic or Relative Dignity?

So how do the individuals and organizations contributing to the “Select Committee on Dying with Dignity” understand dignity? We used the qualitative software NVivo (2010) to identify and categorize the various uses of the term dignity in the hundreds of testimonies. We made a comparative analysis between dignity as discussed by those individuals who were arguing in favour of the right to die (right to die activists) and those who were opposed (anti-euthanasia activists). Some were associated with right to die and anti-euthanasia organizations. Others were not, but they still had an invested interest in the issue that led them to give testimony. The testimonies and discussions organized by the Select Committee dealt almost exclusively with end of life care and euthanasia, and only rarely treated assisted suicide. This is why in this paper, for example, we do not differentiate activists in favour of euthanasia from those who support assisted suicide but not euthanasia. At the risk of possible overgeneralization in dividing schematically between right to die and anti-euthanasia activists, we identified competing discourses on dignity.

This article will not provide an exhaustive analysis but instead highlight what we found to be representative examples of “dignity talk” from these opposing positions. From this meta-analysis of the testimonies, we see several competing meanings that replicate the history of the concept through time in its various competing and overlapping meanings. First, there are those who define dignity as a religious quality that sets our species apart from others. From this perspective, humans are made in the image of God and this is what sets us apart from the rest of life on earth. Such understandings of dignity are in opposition to the right to die. In the words of one testimony: “... the worth of a human being is extremely high and under no circumstances should one treat a human being with disregard or in a manner that violates the dignity he/she has as a creature of God.” (our translation) Thus dignity stems from the sacred character of human life and needs to be protected since dignity is still perceived as vulnerable to violation. In this view, dignity is inherent, natural, inborn, inalienable and cannot be lost.

Another intrinsic definition of dignity exists. Immanuel Kant famously differentiated human beings who have “dignity”, from things which have a price: “What has a price can be replaced by something else as its equivalent; what on the other hand is above all price and therefore admits of no equivalent has a dignity” [14, p. 42]. Kant also explicitly rejected the practice of suicide because, among other

reasons, it entails considering oneself as a means to an end (to escape suffering for instance) and not an end in oneself, as every (rational) human beings should be considered according to Kant. In the 20th century, Ricoeur echoed this sentiment, arguing that, “something is owed to a human being simply for being human” [15, p. 236]. In Québec, this position – that dignity cannot be lost – was voiced by Thomas de Koninck [16]. In his testimony to the committee, he wrote:

For my part I am deeply convinced, and have provided a rationale for my conviction that every human being, whomever he or she may be and whatever his or her condition, is unique and has equal dignity, precisely that of an end-in-itself. Therefore, we can never say or think: “he doesn’t count” or “his life doesn’t deserve to be lived anymore.” (our translation)

Right-to-die advocates argue for more relative and contingent understandings of dignity. In such a view, dignity is subjective and may depend on how the person views, for instance, their physical or mental condition. Dignity may be lost when a person loses autonomy, ceases to be master of their body and/or mind, or experiences unbearable suffering. In another context, Giorgio Agamben in his philosophical analysis of the Auschwitz concentration camp wrote that dignity is not inalienable in the human species and that Auschwitz “marks the end and the ruin of every ethics of dignity and conformity to a norm... and ‘the ultimate sentiment of belonging to the species’ cannot in any sense be a kind of dignity” [17]. In the same vein, musing on the dying process of a friend with AIDS, the author of one testimony wrote: “Robert was literally dying. This was far from human dignity. He died in unimaginable suffering. To say, as some did, that Robert was in his last days ‘the bearer of a unique and inalienable dignity by virtue of being human’ is absurd and even ridiculous.” (our translation)

The Internal Threat and the Human Condition

Right to die activists see dignity as vulnerable and fragile, fraught with both external and internal threats. Violations of dignity can come at the hands of others, but also from our precarious biological existence. In other words, threats to dignity come from our decomposing, decaying, dying, sick and diseased bodies. From this perspective, it is the dying process itself that poses a threat to dignity. This usage stands in peculiar contrast to older assumptions concerning the sources of threats to dignity. As dignity became linked to human rights rhetoric after WWII, including in the UN Declaration of Human Rights, proponents presupposed the existence of threats and violations to dignity but presumed they were at the hands of other human beings, not from our own bodies. Violations of dignity were tied to inequalities, power asymmetries, and exploitation. For example, as Jacobson [18] writes, dignity can be violated by a long litany of behaviours that include the numerous ways in which human beings may treat others badly, among them “rudeness”, “condescension,” “trickery”, “objectification,” “restriction,” “revulsion” and “bullying, assault, and abjection”. In contrast with the right-to-die view that one’s own body may pose a threat to dignity, this litany of behaviours emphasizes external threats to dignity. It assumes violations of dignity are caused by one human being’s actions towards another – whether through working conditions, substandard housing, or torture. In particular, as dignity emerged as a key language of human rights, it was linked explicitly to the censure of torture and other “cruel and unusual” punishments. The US Supreme Court provided a paradigmatic example in the 1972 case of *Furman v. Georgia* when it said that “a punishment must not by its severity be degrading to human dignity” [19, p. 39].

Even when the concept of dignity was used with reference to the dying process, it was specifically in the context of medical technologies bent on prolonging life at all costs. A dignified death was linked to the withdrawal of treatment, that is, removing human interventions (switching off life-support machines, disconnecting a feeding tube, etc.) that were artificially prolonging life against the will of the individual. In the right to die debates, the violation of dignity does not come from the hands of others. It is the dying process itself that renders human beings in a condition of losing dignity. Our very bodies are the source of own humiliation, degradation, debasement, torture, and slavery. This can continue to the point where it even robs us of the basis upon which we can exercise any rights at all. The right

to die involves the right of others to enact (in the case of euthanasia) or help us enact (in the case of assisted suicide) our own volition. The sciences of gerontology and geriatrics – as well as all the incentives to “age well” by taking care of (disciplining) our bodies and brain with physical and mental exercises, appropriate nutrition, etc. [20] – may also be part of this discourse portraying aging as a pathological problem and a potential internal threat to our dignity.

Dignity and Autonomy

When activists appeal to a right to die, they often employ a notion of dignity that could be called “Cartesian” or “modern”. Often considered the “father of modernity,” René Descartes – who himself did not appear to support suicide – argued in *Discourse on Method* that humans should “render ourselves, as it were, masters and possessors of nature.” For Descartes, self-mastery was considered important “for the conservation of health, which is without doubt the primary good and the foundation of all other goods in this life” [21, p. 35]. Not being able to master nature (for instance by losing control of one’s body or mind) is perceived as undignified by some right to die activists. Of course, these activists do not wish to imply that everybody will perceive such a situation as undignified and that it depends upon one’s own individual self-assessment and judgment. However, losing self-mastery is a key precondition for the loss of dignity.

Moreover, in this context, dignity is grounded in rational agency: it is the ability of people to make rational decisions for themselves. As such, dignity is contingent on autonomy of choice. Yet, this framework implies that dignity can be lost. We have dignity because we are autonomous (we have self-determination), independent (we do not rely on others) and can make choices as human beings. Here we can see the issue as part of the emergence of sovereign subjects demanding the right to decide all aspects of their lives, including, in the end, their own deaths. Not allowing choice denies autonomy and consequently robs them of their dignity. In the words of one testimony:

I should have the ultimate right to freely make this choice in peace, harmony, compassion and dignity. In my case, it is the only freedom that remains and it should not be taken away from me, since nobody – I insist, nobody – can tell me what I am going through. Therefore, who can pretend to have the right to prevent me from having this right to die with dignity? (our translation)

The rejection of a paternalistic view lies between the lines of this testimony: nobody, not even the State, can prevent someone from deciding what a person does with their body or how they live or die. Anti-euthanasia activists often disagree with this line of reasoning, rejecting the association between dignity and autonomy by emphasizing interdependence. The author of one testimony wrote: “Upon what basis can we claim that needing other human beings implies a loss of dignity? Every child, from birth until adolescence, is physically, financially, emotionally, and socially dependent; do they lack dignity?”

In the end-of-life debate, ambiguities over autonomy exist. First of all, if the right to die is premised on autonomous choice, why do most pro-legalization advocates or countries allowing these practices – Switzerland being here an exception to this rule – add a series of requirements such as suffering, being terminally ill, etc., to exercise this right? As suggested by Andorno in his review of this paper, this is evidence that “even supporters of euthanasia and assisted suicide do not really think that the foundation of this right is autonomy and free choice, but the idea that, in certain circumstances, life is no more worth living.” We will return to this point later in the article when we speak of a necessary external validation.

Secondly, the Commission also insists that the request for medical aid in dying be made “after a free and informed decision” [2, p. 99]. Yet, at the end of life many people suffer from cognitive impairment that may impede such a decision. Although the report of the Commission originally allowed competent adults to formulate an advance directive for medical aid in dying, it did not authorize a person

suffering from a degenerative brain disease (such as Alzheimer's) to do so. At the time, the Commission recognized the difficulty of addressing this complex issue and concluded that further investigation was needed to propose solutions on this matter. Later, in 2013, Bill 52 was amended so that a request for medical aid in dying could not be formulated in an advance directive (even when the person is competent).

Some right to die activists argue (especially in favour of euthanasia) that someone can enact an ill person's autonomy on their behalf even if they no longer have it themselves. In such a way, autonomy refers to volition and agency rather than bodily integrity. This modern conception of dignity as capacity to make choices and right to equal treatment has a long tradition (Cicero and Augustine for example) but emerged in particular with the bourgeoisie revolution of 1789 [22]. The bourgeoisie used the concept of dignity to promote the idea of a democratic comportment; that the worth of a human being does not depend on their social status but rather on their behaviour [22]. This was in contrast to noblemen's concern with honour. Historically, dignity – from latin *dignus*, 'worthy' – was used in association with a social title to show the worth of somebody [23]. This 'aristocratic' conception of dignity – which has little in common with the modern conception of dignity (implying autonomy and being able to choose the moment of death) or the bourgeois conception of dignity (self-controlled behaviour) – "is not ascribed to all human beings but is a term of distinction" [10]. For instance, in pre-revolutionary France, not all human beings had the same worth; it was difficult for commoners to acquire such a title or 'dignity'. The English (and French) language has kept a record of that meaning in the term 'dignitary' as designating a notable or a person of distinction. On the contrary, dignity for the bourgeoisie is contingent on behaviour. It refers to the quality of character, and "shows itself above all when we exercise self-control in the overcoming of suffering" [13, p. 35]. For this reason, Rosen argues that as an aesthetic quality, dignity is a product of expressions of agency. Dignity is a product of refined performance. In this understanding, dignity is the "ability to act well despite the resistance of our natural inclinations" [13, p. 35].

A recent example of this perspective on dignity can be found in the case of Jane Lotter, a Seattle writer who in August 2013 not only authored her obituary but also her death, taking advantage of Washington state legislation authorizing assisted suicide. In the *New York Times*, her husband described her death with dignity in terms of timing: "It's tricky. You have to do it yourself. Some people wait too long and slip into a coma" [24]. On her last day, she was together with her husband and children, hugged and kissed her family, while pouring the barbiturates, accompanied to the music of George Gershwin's "Lullaby." Her obituary speaks of acceptance of her death, gratitude for her life, and her love for her family and friends. She is even able to joke about it. The guestbook speaks of what a "courageous", "lovely", "inspirational" and "beautiful" way that she died. Rather than an ugly, unaesthetic death – dying in agony hooked up to tubes in a hospital fighting against an inevitable natural process (as the images used in the death with dignity campaign in France that we opened with) – this is considered a "dignified" and "beautiful death". This perception arises since Jane Lotter appears to have acted with restraint, self-control and, as Schiller said at the end of the 18th century, with "peace in suffering" [25, p. 159].

The Necessary External Validation

Right to die activists emphasize voluntary choice. Given the choice, some will decide in favour of ending their lives and others against. This reflects differences in individual's perception of their own dignity, indeed, the deep subjectivity involved with associating the term with particular choices. In the words of one activist during the hearings: "Dignity is personal. Everyone sees it differently. Countless pages have been written on dignity, and no one has managed to define it. It depends on the person, his values and his situation."

Here, dignity is based on self-perception and self-evaluation, what philosopher Arnd Pollmann terms "embodied self-respect" [26]. In this sense, it seems a clear difference emerges, one that the Right to Die committee's final report observed as a tension between an intrinsic dignity that cannot be lost and

a “subjective” dignity stemming from personal autonomy that can be lost. The committee defined the latter as “subjective dignity, which is relative and personal” [2, p. 63]. In their words:

... there is no one better placed to decide whether life is still worth living than the person who is dying. This assessment may be based on the suffering an individual feels, for example, as a result of his declining health. Understood in this manner, human dignity largely depends on how the person views himself [2, p. 63].

The reports’ conclusion was that the law had to subscribe to “subjective dignity” – “otherwise, how do you explain the right to the protection of dignity provided for in the charters if it cannot be infringed” [2, p. 63]. Dignity would only need protection under the law with the presupposition that dignity could be violated. Intrinsic dignity, by its very definition, is inviolable so could not form the basis of a legal framework of protection. The only way to understand dignity was based on individual self-assessment. Since conceptions of dignity varied so widely from person to person, the only way to understand these differences were to subscribe to a notion of “subjective dignity.” Subscribing to this notion of “subjective dignity” consequently involves legally allowing the person to choose to die in order to protect them from losing dignity. For the committee, it logically follows that to protect this “subjective dignity”, the sick person should be allowed to decide at what point their dignity was lost by the suffering or loss of autonomy caused by their terminal illness. Once they made that “subjective” assessment, they should be given the right to die.

However, anti-euthanasia activists do not argue exclusively in terms of inviolable dignity. They also argue against violations of dignity through exploitation by other human beings. Dignity may be inherent so cannot be lost but it is vulnerable to abuse and in need of protection. For this reason, even if right to die advocates point to the numerous safeguards that exist where assisted suicide or euthanasia are legal and to studies that suggest the safety of the practices, anti-euthanasia activists argue that pervasive hidden abuses exist and that assisted suicide and euthanasia invariably present a threat to the safety of vulnerable populations. In fact, their view is closer to the traditional views of human rights and dignity that we identified earlier. To say that some lives are euthanizable or to say that some people can be provided with resources that facilitate their suicides is to say that there is a category of “life unworthy of life” (a term anti-euthanasia activists lift from the Nazis but employ quite loosely). For anti-euthanasia activists, victimization will invariably occur if dying people are allowed to choose their deaths. Choice, they say, is an illusion. They argue that coercion and exploitation, both subtle and overt, will be directed at society’s most vulnerable populations, including at both the elderly and disabled persons. A right to die, they argue, consciously echoing the work of prominent conservative bioethicist Wesley J. Smith [27] who has written extensively on the issue, becomes a duty to die. This idea is reflected in the following testimony:

My father lived a long time in terrible psychological agony. There were numerous witnesses. Nobody did anything. My father didn’t want to die. However, some people made the decision for him. And these people are very well protected by the government: no investigation, no police, no trial, no sentence. (our translation)

Here we are caught up in an inherent ambiguity within “dignity talk.” On one hand, dignity refers to self-esteem and self-worth, one’s own valuation of one’s own life. But, on the other, even right to die advocates argue that external validation is still required, by a doctor or a psychiatrist for instance, who has to verify the physical and psychological condition of the patient. Thus, the right to die requires certain life circumstances to be defined and verified by external actors as worthy of being killed (in the case of euthanasia) or helping to die (in the case of assisted suicide). For instance, the “medical aid in dying” proposed by the Select Committee will be offered only under certain strict circumstances to certain eligible individuals. For anti-euthanasia activists, an externally defined set of categories of “euthanizable” life implies a hierarchical value of life. This harkens back to the definition of dignity we mentioned earlier in which dignity comes from social hierarchy and positions of status/rank.

The Medicalization of Dignity

As early as the 19th century, activists were advocating for laws in Britain and the US, framing for the first time this issue as a matter of public policy and endorsing the medical practice of euthanasia. As Lavi notes, “the modern problem of dying, namely the condition of hopeless suffering for which euthanasia is one proposed solution, predates the technical advances that are so commonly associated with it, such as life-support systems and advanced surgery” [28, p. 4]. In this rhetoric, dignity became relevant only in the late 20th century, when the concept was used to counter processes of excess medicalization. Right to die activists used dignity to counter such processes. Images of intubated, mechanized, confined, immobile and hidden deaths were consequences of institutionalized and medicalized deaths that robbed people of their autonomy and their dignity. The palliative care movement with its holistic physical, psychosocial and spiritual approach to pain was also created in reaction to the inadequacy of the care of the dying offered in hospitals [29].

However, in looking at the recommendations of the Québec Select Committee, one can see that dignity itself has become medicalized. When the Committee released its report recommending the legalization of “medical aid in dying”, the very terminology employed reflected the committee’s argument that euthanasia is medical treatment. They did this because health care falls under provincial jurisdiction and thus outside of Federal criminal jurisdiction where assisted suicide and euthanasia are still criminal offences. However, as dignity has become a notion argued over by bioethicists, activists and medical practitioners in relation to medical conditions and diseases, they have turned it into a medical object; hence why one bioethicist [18] argues that dignity is in need of a taxonomy, a “coherent vocabulary and framework to characterize dignity” [30, p. 15]. The trend is to classify dignity, measure dignity, diagnose it, standardize it, prescribe it to the point where it becomes not only a medico-technical object but also an assumed value, something utterly normalized, a value that no one can refuse. The select committee argue this in their final report. Acknowledging the lack of consensus on dignity, they argue that because it is invoked by both right to die and anti-euthanasia activists alike, “the name of the Select Committee could not be more appropriate, since this concept is paradoxically unifying” [2, p. 63]. As discussed earlier, the value of this kind of “discursive catch all terms” [31, p. 161], like “dignity”, “freedom” or “justice” for instance, lies certainly in its power of mobilization. Being “nodal points” [7], they are able to gather up different terms (like autonomy, end-of-life) and various social movements around them.

The Narrative Production of Dignity

Dignity has been adopted as a fundamental guiding principle not only with reference to euthanasia but increasingly in biomedical understandings of the dying process. Nowhere is this more evident than in another Canadian site of “dignity talk” in the work of psychiatrist Harvey Chochinov of University of Manitoba and inventor of so-called “Dignity Therapy” [32]. Part of Chochinov’s approach has been to create a “novel 25-item psychometric instrument” called “the Patient Dignity Inventory” (PDI). Tremendous resources have been devoted to this project, which has been featured on US National Public Radio (NPR) and Canadian Broadcasting Corporation (CBC) and published in influential journals [32]. In 2012, Chochinov was recipient of the Canadian Medical Association’s highest honour, reflecting the view that dignity therapy is a significant novel therapy of the 21st century and a model to be exported elsewhere.

Social scientists looking at dignity therapy may recognize it as a normative, quantitatively repackaged version of what medical anthropologists like Arthur Kleinman [33] were doing three decades ago under the guise of illness narratives. After all, dignity therapy involves the production of a narrative that allows dying individuals to “find meaning” in their lives (and thus find dignity through embodied self-respect) via the production of a packaged life history biography. The biography that can be handed to family members to share memories, voice experience, discuss lessons learned, and find larger significance in illness and death. If the dying process can entail a loss of meaning and value in life, dignity therapy aims to restore it.

Canadian anti-euthanasia activists like Margaret Somerville [34] have seized upon dignity therapy, arguing that with it, the need for euthanasia and assisted suicide disappear. Right to die activists see Dignity Therapy as an affront: one right to die activist's blog post reads the "Indignity of Dignity Therapy" [35]. Dignity Therapists remain silent on the issue but perhaps its belief that suicidal ideation among the dying is something pathological reveals its assumptions. For right to die activists, the desire to end one's life under an agonizing dying process is a rational response to one's conditions of life and thus should not be pathologized. In fact, right to die activists reject the notion of suicide altogether. The encouragement towards narrative accounts is echoed in other movements organized around biological processes. Analysing the general process of decriminalization of different medical practices (i.e. abortion, in vitro fertilization), Dominique Memmi writes that narrative accounts provide a necessary counterpart to these practices, "a biographical account, measured in the light of a legitimate account expected by experts" [36, p. 8]. This "policing of narration" has taken the place of the old "corporal police." Regarding the end-of-life debates, Memmi argued that this "secular confession" to experts – often physicians – is in fact encouraged by both the palliative care and right to die movements: "Some (Association for the Right to Die with Dignity) make an effort to recognize an unusual "right to speak" of the dying that would permit them to "specifically express their wish in writing". Others (Palliative Care) constantly want to "make death and the dying talk", "talk to understand better" and teach "how to die" [36, p. 8]. Indeed, both movements encourage one to "listen to the patient", and to collect, like Dignity Therapy, the account of his/her death.

This encouragement to narrate evokes the work of Michel Foucault who associated this "urge to confess" in Western culture with the ruse of modern power that paradoxically maintains an impression of freedom yet acts at different levels at the same time to sway the population. For Foucault, "one has to have an inverted image of power in order to believe that all these voices which have spoken so long in our civilization – repeating the formidable injunction to tell what one is and what one does, what one recollects and what one has forgotten, what one is thinking and what one thinks he is not thinking – are speaking to us of freedom" [37, p. 59-60]. In this quote, Foucault urges us not to mistake the invitation to talk – like in so many talk shows, magazines and other media for instance – for true freedom. Both the palliative care movement and the right to die movement promote the "right to speak" at the end of life. The former does so in order to encourage people, through narration, to accept peacefully this inevitable moment. The right to die approach sees the right as entitling people to "speak up" and decide when to die. In any case, underscoring the importance of "talk" at the end of life has become a new norm wherein a good death is a dignified death, which today entails a "confessed death" narrated to health care professionals.

Normative Dignity

All this discussion contains a structuring absence. What about those who do not wish to see their lives in the language of dignity? Dignity Therapy, in its own self-assessments, works well for those who want it yet acknowledges that some refuse to participate. Bayatrizi [38] has argued that modern cultural attitudes towards death can be understood as "strategies of ordering death". To do so, she argues, different discourses have been developed since the 17th century as responses to the various societal threats (political stability, depopulation, etc.) that are caused by "disorderly deaths." Bayatrizi summarizes this injunction in a quasi-biblical way: "thou shalt not die an undignified death." She asks the question: "If modern Western culture is obsessed with prolonging life, as is often charged, why does it allow and even institutionalize certain forms of voluntary death?" [38, p. 159] For the author, postponing death as well as legalizing euthanasia are both ways of ordering death that emanate from a "fear of its unruly and disorderly manifestations" [38, p. 159]. Divergent discourses on dignity come from organizations that disagree on the way to "order death" but all suggest how we should die, albeit with varying degrees of righteousness. These normative calls all take for granted that all human beings wish to die with dignity (in an ordered and aestheticized way). For instance, the latest book of influential French palliative care psychologist (and right to die opponent) Marie De Hennezel is called: *Nous voulons tous mourir dans la dignité* (We all want to die with dignity) [39]. This normative dignity

is also what is implied by the testimony of the “Collectif Mourir digne et libre” (Collective for a dignified and free death): “In fact, the question now before us is how to guarantee that everyone can end their lives by dying in dignity and peacefully and not just those favoured by the current medical and legal framework.” (our translation)

In this sense, dying with dignity becomes synonymous with having “a good death.” A guiding assumption of the right to die movement (as well as the palliative care movement exemplified before by Chochinov’s “Dignity Therapy”) is the need to have a good death and is thus wedded to notions of normative dignity. We will cite two separate examples. In North America, anti-euthanasia activists’ most frequently used examples of the inevitable “slippery slopes” of assisted suicide is the case of Barbara Wagner. Diagnosed with terminal lung cancer in the state of Oregon where assisted suicide is legal, Wagner with her doctor’s support requested an experimental chemotherapy drug as a last resort. Her Oregon Health Plan declined coverage, arguing that the treatment was not proven to be efficacious. Instead, they wrote that they covered “comfort care” – palliative and end-of-life treatment that included among other options assisted suicide or “physician aid in dying.” As the case circulated and generated public controversy (to the point of it being used by the anti-euthanasia movement to support the idea of government “death panels”), Barbara Coombs Lee, the president of Compassion and Choices, the US’s largest right to die advocacy group, responded in an editorial, accusing the media of sensationalizing the debate. Arguing that Wagner’s expensive experimental medication constituted “futile care” and thus should not have been covered, Barbara Coombs Lee criticized “last hope” treatments with “toxic side effects” and blamed doctors who may not inform patients of “the true statistical chances these therapies will prolong life” [40]. Her conclusion was that this case was a product of society’s “collective denial of mortality”. In the end, Wagner’s refusal of a good death was the core issue. In other words, a dying adult should be able to rationally and statistically calculate whether a treatment’s potential life-extending benefits outweigh its potential side-effects and if the side effects are too harsh and the treatment has not a high enough chance of working, they should accept that they are dying and peacefully engage with the dying process with all its Kübler-Rossian stages of denial, anger, bargaining, depression and acceptance [41]. “Enlightened moderns” should embrace the ideal of a “good death” with all of its platitudes is one of the key assumptions of the right to die movement.

Within this model, the final stage of acceptance is most important. One must accept that one is dying and not fight against a natural process. Embracing the dying process not only provides personal closure but also solace to loved ones. But what about dying people who refuse these comforts? Here, we can not only speak of Barbara Wagner but a critical thinker and “enlightened modern,” Susan Sontag. Her son, David Rieff’s memoir [42], details his mother’s difficult death that resulted from her refusal to accept that she was dying given a recurrence of cancer and terminal diagnosis. With no hope but terrified at the prospect of her own demise, she pushed for every and any kind of experimental treatment no matter the side effects. Rieff himself would wonder how someone who had such a strong critical eye and a firm belief in truth as a noble pursuit could deny her death. In the end, her drawn out and painful death did not provide solace to her kin, who could never discuss directly with her that she was dying but were forced to play along with her misapprehension of hope. Her fight to live would not be seen as courageous. Courage comes from facing one’s death and not denying it. Nor would it be seen as a good death since it was an agonizing, protracted, and messy one. In this sense, it was not a “dignified death” by the standards of the “death with dignity” movement.

Why assume that it was wrong or unseemly for Barbara Wagner or Susan Sontag to die the way that they died? Why assume their deaths were undignified? Such a variety of temperaments and lives can be found among the living but yet should we assume that all people should die with dignity? As David Rieff wrote in his book, Susan Sontag “died as she had lived: unreconciled to mortality”. Susan Sontag’s final moments remind us that having a “good death”, which today implies “dying with dignity,” is not necessarily desirable for everybody. To illustrate this point on a lighter note, we are reminded of an old episode of *Seinfeld* involving noted philosopher of pessimism George Costanza. In the show, George panics after his doctor discovers something suspicious during a routine check-up. He jumps

to the conclusion that he is dying. Turning to his friend Jerry for moral comfort and support, Jerry, characteristically, responds “Can’t you at least die with a little dignity?” To which, George says, “No I can’t. I can’t die with dignity. I have no dignity. I want to be the one person who doesn’t die with dignity. I live my whole life in shame. Why should I die with dignity?” George’s refusal of dignity and desire to die in, his own mind, the same manner that he lived is not just a sitcom punch line but perhaps an eloquent lesson that points to what all this “dignity talk” in its polysemous multiple related meanings may take for granted. Whatever conception of dignity that is employed by either side of the debate, all assume dignity is both ultimate human good and goal that must be protected or fought for at all costs. We can argue about what dignity means and which definitions to employ, but its ultimate value as mandatory, non-negotiable norm and value remains taken-for-granted. Dignity has become the inescapable terms of debate.

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