Panel T08P14 Session 2

Policy Narratives and Public Policy

Title of the paper

The narratives of end-of-life policy: How dying becomes a policy issue?

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Date of presentation

June 30th

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<u>INTRODUCTION</u>

End-of-life is a delicate problem, being at the same time a very personal issue which takes roots in ethics, values, emotions and spirituality; a health concern that questions the diversity of care available, an economic catch that highlights the cost of health care; and a legal problem as it involves rights and responsibilities. Addressing this issue requires a reflection that includes, among others, concerns about individual autonomy, patient-doctor relationships, control over medical treatments, roles and relationships with relatives, and quality of life (Castra, 2013). It raises the immense question of individual and collective rapports to life and death, in itself, an immeasurable public issue.

Because it addresses the relationship between death and life, but also because it implies more than the individual, end-of-life is a complex problem that been on the political agenda of Western countries for several years. A number of countries have already adopted legal frameworks to address it[1], most of which focus on assisted suicide (helping the patient commit suicide by providing lethal substances that the patient self-administers) or voluntary euthanasia (administration of substances, usually by a physician, that cause death). For example, the states of Oregon (1997), Vermont (2013), Washington (2008) and California (2015) allow only physician assisted suicides. The Netherlands (2002) and Luxembourg (2009) permit physician-assisted suicide and voluntary euthanasia. Belgium (2002), Columbia (2015) and Canada (2016—Québec in 2015) allow voluntary euthanasia.

Discussion around euthanasia and assisted suicide periodically comes back in the news, particularly following the medialization of dramatic cases such as the ones of Terri Schiavo in the US, of Ramon Sampedro in Spain, of Sue Rodriguez and Robert Latimer in Canada. In Québec, it was the cases of two women named "Marielle Houle", one having helped her handicapped 36-year-old son to die in 2004 and the other, a woman with a degenerative disease that left her severely handicapped and whose husband helped her die in 2005, that revived the debate. These two cases were followed by the introduction, in 2005, of a private bill in the House of Commons aiming at amending the Criminal Code to allow "the right to die with dignity". Although that bill was defeated, it paved the way for the present law, the *Act respecting end-of-life care,*[2] adopted in June 2014 and implemented in December 2015.

Discussions on this issue in Québec really took off after a publication from the Québec Physicians Board in 2009. Their report reframed the debate around decriminalizing euthanasia

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[1] http://www.justice.gc.ca/eng/rp-pr/other-autre/adra-amsr/adra-amsr.pdf
[2] http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/S-32.0001

into a question of appropriate end-of-life care[3]. This report opened the door to a Special Commission that held public and targeted consultations between 2009 and 2011[4]. In 2012, the Québec government issued the report "Mourir dans la dignité" (Dying with dignity). This report proposed 24 recommendations that were later reviewed by a committee of experts who concluded that "medical aid in dying be understood, in certain circumstances, as part of the continuum of care". Bill 52, the *Act respecting end-of life-care* was presented at the National Assembly in 2013 and adopted in 2014. The law was implemented in December 2015[5] and defines "medical aid in dying as "*care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death*". (Québec, 2017).

This Act is rather fascinating from a policy analysis perspective. First, it is a concrete example of a rather radical policy change. Being the second most populous province in Canada (after Ontario-13.6 millions) with 8.2 million, Québec was the first province to implement a legal framework to manage end-of-life decisions in Canada. Québec was quite innovative in addressing such a sensitive issue and has, therefore, created a precedent inciting other provinces (Ontario namely) to start reflecting on the matter. Second, the act provides an opportunity to study policy framing of recent decisions as opposed and complementary representations of the problem. Policy framing deals with interpretation and representation of public issues, their consequent effects on deliberations and interests, the type of conflicts and actors involved (Weiss, 1989) and the choice of policy instruments. Framing helps *make sense*, in other words, locating, perceiving, identifying and labelling the issues that arise (Schoen and Rein, 1996). Because of the nature of the issue, the *Act respecting end-of-life care* puts forward a certain conception of what the end of life is and of its modalities of inclusion in a continuum of health care. Moreover, a range of stakeholders and stakeholder networks have been involved directly or indirectly in its formulation. Because of their identities, their social functions, their interdependence and their policy roles, these actors constructed different interpretations of the problem based on several themes (such as dignity, autonomy, medical aid to die and sanctity of life) whose meanings vary. Finally, because the Quebec Act deals with issues of life and death, it can be studied from a morality policy perspective. This literature concerns highly emotional policy such as gambling control (Ferraiolo, K., 2013), death penalty (Mooney and Lee, 1999),

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[3] http://web1.ledevoir.com/societe/ethique-et-religion/275511/position-du-college-des-medecins-autoriser-l-euthanasie-dans-un-contexte-de-soins-de-fin-de-vie

[4] 32 experts heard, 272 written submissions, 239 persons heard at public hearings across the province, 114 people heard during open microphone periods, 6558 respondents to online questionnaires, more than 16,000 comments received by various means of communication (Assemblée nationale, 2012).

[5] Bill 52 established rights with respect to end-of-life care, rules for those who provide end-of-life care, rules relating to continuous palliative sedation, powers of the Minister of Health and Social Services (Minister), rules relating to advance medical directives.

regulation of prostitution (Schmitt et al., 2013), drug use (Euchner et al., 2013) or abortion (Mooney and Lee, 1995). Morality policy is linked to conceptions of morals or "mores", "*which are commonly held beliefs among communities derived from cultural norms*" (Studlar, 2001, p. 37). A conflict between mores necessitates a particular codification of values in society (legislation), thus giving rise to morality policy (Ibid). It is therefore worth asking the question of how end-of-life, a matter generating conflicts of values on which trade-offs are difficult, was framed as a policy issue in Québec.

Little research is actually done on the relevance of morality policy literature to study public policy in general (Knill, 2013, Hurka, 2013) and end-of-life policy in particular. Recent research on end-of-life policy opts for a medical approach (Boivin et al., 2015; Landry et al., 2015; Kaufert et al., 2013; Zimmerman, 2012; Marchand, 2011; Goodridge, 2010; Haider-Markel et Joslyn, 2004) or focus on psychological (Gamliel, 2012) and legal aspects (Schafer, 2013; Judo, 2013; Steunenberg, 1997; Meisel, 2003). Very few are interested in the media representation of the issue (Birenbaum-Carmeli et coll., 2006 ; Haller et Ralph, 2001 ; Marcoux et coll., 2007, Yeatts, 2000) and even less in the use of narratives to inform the debate (Kaufert et al, 2011; Verbakel and Jaspers, 2010).

In order to fill that gap, our study adopts a *framing* perspective on morality policy to understand policy change. An analysis of the rhetorical foundation that has generated the recent policy change in Québec has therefore been conducted through a systematic review of the province newspaper articles (editorials and Op-Eds) published between 2005 and 2015. This paper presents the first part of this analysis, concentrating on the *opinion articles (Op-Eds)*. From these, four narratives framing the debate that led to the adoption and implementation of the *Act respecting end-of-life care* were drawn: "The legal is not the moral", "No dignity without autonomy", "The lucrative Pandora's box" and "Liberating death".

Framing and morality policy as lenses to study end-of-life policy

Tversky and Kahneman (1986) initially discussed the concept of framing as an alternative explanation for rational decision-making. The authors argue that different solutions will be chosen depending on the affectivities (and preferences) of the actors. For example, the same information presented positively or negatively will influence opinions about a given issue differently (Druckman, 2004). Studying problem framing sheds light on dimensions that will be included and excluded from public discourse (Fischer, 2003). Indeed, several authors have examined the effect of framing in various policy fields, such as positive discrimination (Kinder & Sanders, 1990), health care reforms (Stone 2001), gun control (Callaghan and Schnell, 2000),

feminist movements (Mazur, 2009), or welfare reforms (Streensland, 2008). Policy framing study facilitates the recognition of competitive conceptions and interpretations of interest groups, policy makers, experts and citizens of a social problem, as well as possible solutions. Besides, Schoen and Rein (1994) have shown how public policies are built on perceptions, beliefs and subjective evaluations and demonstrated that not only do preferences for a given framework provide a justification for the proposed solutions, it also changes the problem in itself. Policy framing is therefore the product of interpretations and reconstructions of information (Fischer, 2003) and compares itself with the concept of social representation (Negura, 2006; Moscovici, 1988) which fosters the idea that public policy emerges from a *socially constructed world* that provides explanations on the importance and the democratic possibilities of civil society, on targets of public action and on preferred values in the policy process (Ingram and Schneider, 1993, 1997). Social representations are a *sociocognitve construction* (Abric 1994) since they originate from the communication (social dimension) of individual perceptions (cognitive dimension).

Social representations of the end of life are far from being static or unique or even exclusive. For example, discussing the notion of *dignity*, Baudot (2005), shows how the "taboo of death" thesis in France was carried by social actors between the 70s and 90s and how it led to the incursion of non-religious actors in the debate through the constitution of expert knowledge about dignity. This notion was used both by the supporters of the right to die (whether conceived as euthanasia or assisted suicide) and by their opponents for different reasons (Behuniak, 2011). Arguments about aging of the population and its effects on health care, the resulting economic constraints and the relationship between dignity and individual freedom about one's own death contextualize discussions and decisions about end-of-life care (Desgranges, 2013). Thus, beneath the simple notion of dignity, several individual representations are included and excluded from end-of-life policy framing (Misztal, 2012), but nevertheless contribute to its construction.

Although not much can be found in recent literature end-of-life policy framing, a number of authors have written on the media construction of assisted suicide. Birenbaum-Carmeli et al (2006) studied three cases of assisted suicide performed by family members (and convicted) in Great Britain between 1996 and 1998 through a textual analysis of their media coverage. The authors identified four themes: the character of the deceased (hero—autonomous or dependent), the perpetrator of the crime (worthy individuals caught in unhappy circumstances), families (consensual) and the state (oppressor). The authors highlight the political importance of media representations in that "*the narrative of the courageous individual who refused to go on living a hampered life dovetailed with neoliberal discourse of the entrepreneurial individual and the related motion towards*" (p. 2161). Similarly, Gailey (2003), in a book on the Kovorkian case, analyzes how the media framed the discussion into two main frames, medical and legal, and this,

whether actors were pro-life or pro-right-to-die. Kalwinsky (1998) also demonstrated that media portrayals of assisted suicide tend to emphasize the voices of doctors and courts rather than patients, and ignore class and gender issues. In parallel, Holody (2011), in a study on the links between media coverage of assisted suicide and people's opinion on the subject, shows that the legal framework was the most common in news coverage but that respondents' opinions were predicted by their prejudices and personal frameworks about assisted suicide, and not necessarily by the media they used to get information framed the issue.

Policy framing is therefore particularly relevant for analyzing policy with strong emotional charge that usually aim to regulate social norms and undoubtedly lead to conflicts of values (Mooney and Lee, 1995; Mucciaronni, 2011). Bowen (2012) explains that the role of morality policy is to provide "*a lens that can be used to gain insight into the creation, implementation, and effects of policies that attempt to regulate personal and moral behavior*" (p. 122). An important part of the literature defines and describes morality policy as a particular category of policy because of its specific features: first principle, technical simplicity, salience, public interest and public participation (Mooney, 2001; Mooney & Schuldt, 2008; Studlar, 2001; Bowen, 2012; Arsneault, 2001). Issues of first principles means that policy addresses questions of right or wrong, producing value-based conflicts on which compromises are difficult (Mooney, 1999; Mooney & Lee, 1995). As matters of first principles, such issues naturally draw on criminal law, which is distinctive of this policy type (Knill, 2013, p. 315). The involvement of criminal law results in unique challenges for implementation as well as enforcement as agencies often have some discretion in applying the law (Ibid). The purpose of the policy may be more symbolic, rather than result-focused, in that it communicates a value statement and not clear objectives and measures, which also contributes to problems with implementation (Wagenaar & Altink, 2012, p. 284).

Morality policy is often understood to be technically simple. "Because," as Mooney (2001) explains, "*the debate is about first principles, not instrumental policy impacts, almost anyone can legitimately claim to be well informed*" (p. 7). Expertise is not needed on such issues in order to have an opinion, as opposed to ones that would require expertise to evaluate environmental impacts or the statistical significance of various studies. Instead, questions of morality policy come down to questions of right and wrong and the fundamental beliefs—rather than technical knowledge—that individuals have on certain issues. As well, in part due to their simplicity and personal relevance, such issues may be more salient to the public and thus can be engaged with more easily, heightening their political significance and visibility, leading to higher than normal public participation (Mooney, 2001; Haider-Markel & Meier, 1996; Studlar, 2001, p. 39). Put differently, morality policy is "lay policy" in that it "*is owned by everyone, while sources of technical authority that might arbitrate conflicts of belief or opinion are either absent or*

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drowned out" (Wagenaar & Altink, 2012, p. 283). These features also give the media a heightened role in the policymaking process as they can inform and sway public opinion (Ibid).

Policy can be categorized as "moral" either because issues have moral *a priori* status (substance) or through communications involved in issues (framing), whereby actors engage on the issue on the basis of or with appeal to morality (Heichel et al., 2013, p. 319)[6]. Substance definitions, also referred to as "content-based understanding" definitions (Engler & Dumig, 2016, p. 3), are those that define morality policy on the value-based nature of its issues (Heichel et al., 2013, p. 319). As described by Camobreco and Barnello (2008), "*these policies have in common a perception that much more than just policy questions are at stake in the political struggle over them. Rather, conflicts over morality policies are conflicts over deeply held fundamental beliefs about right and wrong*" (p. 49). It is the role of deep, moral beliefs that gives these policies, in the substantive view, their particular character (Clifford et al., 2015, p. 229). They emphasize the *regulation* of values, rather than the material questions of economic policies, are at its core (Studlar, 2001, p. 38-39; Studlar, 2013; Heichel et al., 2013, p. 320; Braun & Jörgens, 2013, p. 1).

Although substance definitions are commonly referred to by authors, ultimately, they link them to framing definitions. It is then the agency of the actors involved that determines what constitutes morality policy based on how they present and talk about the issue. Framing processes, as such, create morality policies as they lack an "a priori" existence (Euchner et al., 2013, p. 373). Frames are invoked by actors who are defending their values against a perceived threat (Rapp et al., 2014, p. 422; Omori, 2013, p. 520), or against "sin" (Meier, 2001).

Our study adopts a *framing* perspective on morality policy, particularly borrowing from Mucciaroni's contribution (2011). The author maintains that morality policy do not exist per se

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[6] For some authors, moral issues are triggered by whether or not they touch on other cleavages in society, specifically religious-based cleavages. Engeli et al. (2012), root their theory of morality policy in understanding how religious cleavages in the party system impacts the manner in which moral issues generate different politics. They advance a "two worlds of morality politics" theory that traces particular policy processes and political effects to whether or not a morality policy issue has been raised within a "religious" or "secular" country. Secularization and religiosity are not defined as whether or not religion is present in the society at large, but about the "*role religion, religious actors and arguments play in the political system*" (2012, p. 19). The distinction between the two worlds, relates to "*the existence or non-existence of a religious-secular party conflict*" (p. 14). Morality politics, therefore, are not merely a matter of the substance of the policy issue nor the frame being applied, but also the institutions and history in which morality policy issues arise. Institutional structures, history, and societal cleavages that are manifest in political parties are deeply implicated in defining how morality policy processes and their politics unfold. Similarly, Braun and Jörgens (2013) link morality politics to societal "cleavages", but also draw in the agency of actors who can trigger a morality issue—or demoralize an issue—by linking—or uncoupling—a policy to such a cleavage. This is similar to framing but links clearly to societal cleavages, rather than simply to being a matter of morals or values.

and should be defined as "one of two broad strategies for *framing* issues" (p. 188): **moral and rational-instrumental**. The author argues that some issues (abortion, death penalty, assisted suicide, drug use, gambling, etc.) carry important economic dimensions and are far from being technically simple, cannot be reduced to good/bad dichotomous moral judgments, cannot be strictly based on personal moral positions (which can be put aside) and may raise moral issues but never reach the formal agenda. Unlike other authors (Haider-Markel & Meier, 1996; Mooney, 2001; Kreitzer, 2015) whose view of framing involves at least one actor using a moral frame, Mucciaroni considers a morality "frame" to be about how actors prioritize particular values. Specifically, "*morality policies concern 'threats to core values' not because the values are 'core' but, at a more fundamental level, because those who frame the issues place adherence to moral principles above alternative considerations*" (Mucciaroni, 2011, p. 191). The moral frame is contrasted against another strategy, the "rational instrumental policy" frame, "*in which we judge policies as valuable only if they help to produce desired results*" (Ibid). Instead of the principles, it is the products of policy that are of interest. For instance, a moral frame may address drug use as that of either condoning or preventing immoral behaviour, as opposed to a rational instrumental frame that may discuss the issue as a public health issue, looking at how to improve overall societal outcomes in terms of lowering overdosing rates. With rational instrumental framed issues, compromise and collaboration are possible, rather than moral issues that are indivisible and may result in an intractable controversy. Likewise, Ferraiolo (2013), adopts Mucciaroni's argument on framing to evaluate "moral talk" on issues, further differentiating the types of frames that may be involved and how they are used. For instance, sometimes rational-instrumental arguments are used on traditional moral issues, whereas politicians may also appeal to moral values on non-traditional morality issues (i.e. the environment) as a political strategy (Ferraiolo, 2013, p. 236). Framing may help to explain why the same issues may, in some countries, be approached in a more rational-instrumental way or in a more intense moralized way, depending on how actors manage to frame the issue (Studlar, 2008, p. 393). Finally, Mucciaroni further differentiates frames in terms of those that are **"fully framed"** if both sides of the issue use the same type of frame, or **hybrid** if each side uses a different frame (p. 193).

Mucciaroni's and Ferraiolo's insights makes it possible to *reconstruct* the narratives by first *deconstructing* the selected newspaper articles through stakeholder's positions around the following questions:

1. Which frame, moral or rational-instrumental dominates the end-of-life debate in Québec?
2. What types (or themes) of arguments do they put forward?
3. Is the issue "fully framed" or "hybrid" and how?

METHODS

A search for articles published between 2005 and 2015 (before the implementation of the Act) in Québec newspapers (French and English) was conducted using two data base: *Eureka* for French newspapers and *Factiva* for English newspapers. The search query was based on a combination of keywords[7]. Articles retained had to deal specifically with the draft bill. Redundant or off topic articles were excluded, for a total of 493 articles. Out of these, 318 are general articles (news, editorials, chronicles) and 175 are opinion articles (Op-Eds). Out of the 175 opinion articles, 39 were excluded because they did not present any explicit argument or position on the proposed bill, for a final selection of 136 opinion articles. This paper presents the results of the narrative analysis conducted through content analysis for opinion articles (Op-Eds) only. Public opinion has been an object of study to understand how it shapes morality policy. Camobreco and Barnello (2008), for instance, find that public opinion can be more effective in shaping legislator behaviour than elite opinion. Likewise, Norrander and Wilcox (2001) find a link between particular policies and public opinion.

Articles were coded in two rounds via NVivo11. In the first round, all articles were loosely coded, looking for end-of-life definitions/descriptions and framing indications. The first round permitted to get familiar with the material and plan the second round. In the second round, coding was narrowed to apply Mucciaroni's analysis and identify:

1. Category of actors and gender
2. Position held by actors:
   a. For
   b. Against
   c. Nor against or for
3. Types of framing put forward:
   a. Moral
   b. Rational/Instrumental
   c. Mixed
4. Nature of the arguments for both the moral and instrumental frame
   a. Moral (nature of deontological argument. E.g.: "liberty")
   b. Rational/Instrumental (nature of actual or expected consequences. E.g.: "waste of resources")

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[7] Search query for <u>French articles :</u> "loi 52" OR "euthanasie" OR "droit de mourir dans la dignité" OR "mourir dans la dignité" OR "soins de fin de vie" OR "soins palliatifs" OR "aide au suicide" OR "suicide assisté". For <u>English articles</u>: "bill 52" OR "assisted suicide" OR "end-of-life care" OR "palliative care" OR "euthanasia" OR "dying with dignity".

Four framing narratives were drawn from the analysis, representing both sides of the issue. Two are established on moral arguments: "*The legal is not the moral"* (opponents to the bill) and *"No dignity without autonomy"* (proponents to the bill). Two are based on rational-instrumental arguments: "T*he lucrative Pandora's box*" (opponents to the bill) and "*Liberating death*" (proponents to the bill).

FOUR FRAMING NARRATIVES TO END-OF-LIFE

General overview of the opinions published

The first thing that stands out of the 136 opinions articles published between 2005 and 2015 is the important gap between the number of positions "for" and "against" regulating end-of-life care, opponents being almost twice as numerous (60% vs 36%). If only the years between the beginning of the hearings of the Special commission and the adoption of the bill (2009-2014) are taken into account (124 articles), which could be considered the most important years to voice an opinion to potentially influence the debate, the proportion of opponents (60%) and proponents (35%) still remains the same. The second thing that is equally striking is the very low number of women (32%) who voiced an opinion on the matter between 2005 and 2015 (among which 65% are against) compared to men. Thirdly, although it is not necessary that surprising, 49% of articles framed the issue on moral terms, 36% referred to rational/institutional arguments and 15% framed the issue both as a moral and a rational/instrumental question. What is more interesting, however, is that out of the number of proponents (49 articles), more than half (53%) framed the issue on moral grounds, whereas only 31% framed it as rational/institutional one. Conversely, the opponents (81) to the bill used moral arguments (48%) and rational/institutional ones (37%) in relatively the same proportion. Finally, among those who framed the issue as both a moral and rational/instrumental one (20 articles), more than twice were opponents (65%). These last two observations led to dig further on the details of the arguments put forward by opponents or proponents in their choice to frame the issue either on moral or rational/instrumental grounds.

For proponents or opponents who framed the debate in moral terms, four main themes were invoked: sanctity of life, individual autonomy, dignity and humanity/compassion. On the other hand, abuse/slippery slope, service reduction, protection of the most deprived and individual and social consequences composed the rational/institutional position.

Moral narrative 1: The legal is not the moral

Sanctity of life is one of the most often cited arguments to justify opposition to the bill. This argument, based on religious beliefs, puts forward the idea that regulating end-of life is inadmissible for the simple reason that life is *lent* to human beings before transforming itself into something greater—*immortality*. In that manner, the physician's role is to protect life and integrity. Sanctity of life is defined as one of the most important values in society that cannot be sacrificed for the sake of a few who evoke the right to freedom: "*Assisted suicide and euthanasia undermine the duty to live that mobilizes all our daily actions*". Other interests than the ones preserving life are seen as suspects, hiding self-serving benefits detrimental to society. The expression "assisted suicide" is also often deconstructed to demonstrate that it is a murder in disguise (Free translations):

> *Language acts as a seductive cosmetic: we speak of compassion when it comes to murder. We speak of medical care when it is the last injection that kills.*

> *There is no doubt that the doctor, becoming an accomplice in a homicide, because isn't it necessary to call things by name, which the law does not do, will create mistrust among hospitalized patients and among the population.*

> *A society that justifies this practice is bound up with a culture of death and the fear and anguish that surround it. On the contrary, accompanying a person dealing with a degenerative or end-of-life disease requires openness to others and courage.*

To sanctity of life, *dignity* and *humanity/compassion* are also an important argument to those opposing the implementation of the bill. Interestingly, as will be discussed in the next narrative, it is the same arguments put forward by proponents who frame the issue as a moral one. For opponents, however, dignity touches on something different. It is the basis upon which respect for life is possible. Some extend the necessity to preserve the dignity of the patient to people (namely the physicians) who would be involved in the *fatal act* through compassion and respect for humanity:

> *Is human dignity truly bound up with the mechanics of personal hygiene? Or is dignity more about the intricate chemistry of how we are held in care and regard by those who stand near? Is autonomy really the blunt "carte blanche" of individual will? Or is it the pulsing engine of the warrior's heart, hell-bent on its defence of a vital, expressive, even if diminishing, self? The alternative idea of dignity and*

autonomy is what people with long-standing disabilities can be heard saying, if and when courts and media pause to listen.

Freedom of choice? No matter if euthanasia is wrapped in cotton wool, to make the decision to receive an injection that will bring an abrupt end to our days is the most intense anguish. A decision that is not at all serene, nor does it bring dignity to anyone. Especially if it was not human stupidity, we could already do otherwise (Free translation).

Moral narrative 2: No dignity without autonomy

The notion of *dignity* in this narrative is conceived as something very personal that cannot be understood as a universal concept: "*each one must be allowed to legally enact his/her will so that in desperate situations human dignity is respected*" (Free translation). In comparing dignity to a right, most articles rely on personal stories of family members, usually parents, who did not die as they would have wanted to, as if that final life stage had been taken out of their control:

If you ask me if my father died with dignity, I surely answer NO! Would he have wished to die with dignity? Of course! No one deserves to finish his days this way. (Free translation)

The problem is not in the quality of care received, but in the fact that my mother's wishes were not respected. She died exactly as she did not want to, slowly! (Free translation)

Dignity goes hand in hand with *individual autonomy* as the latter becomes the expression of dignity, some articles even proposing that not respecting it leads to *dignify* suffering. Personal autonomy means taking control over our own destiny as well as over the medical system: "*I consider that it is the strictest right of every human being to refuse to be subject to the dictates of doctors, to refuse to be subjected to the therapeutic persistence of which modern medicine abuses with impunity, to refuse to have to suffer an atrocious death because 'medicine can no longer do anything'*" (Free translation). Individual autonomy, similar to sanctity of life in the first narrative, rests on important moral values, albeit individual ones. If it is not contested that physicians cannot be compelled to perform assisted suicide, it is however, clearly stated that patient cannot be refused the right to decide how and when to end his/her life. As such, respect of individual autonomy is considered closer to humanity. Opposing the sanctity of life argument that life has been lent to human beings, freedom, is put forward as something that is *given*. From that perspective, *life* is not sacred but the *person* is and therefore, "*it is up to the person at the*

end of life to adopt the strategy that suits him/her best, that is, the one that allows him/her to relieve his suffering as much as possible or quickly put an end to his/her life" (Free translation).

> *We all have the right to refuse medical treatments and doctors routinely refuse to perform inappropriate or unnecessary treatments for patients who request them. To maintain that assisted suicide is or should be any different smacks of high-handed paternalism and attacks free will and self-determination.*

> *The appreciation of the quality of life must rest with the patient. Again, it is the autonomy of the patient that must be respected. Let him/her have what is left to him/her, that is, to decide his/her end. No matter what we think of it, death will knock on his/her door, not our own.* (Free translation).

In this second narrative, *humanity and compassion* are seen as the necessary quality to understand what dignity truly means. Contrary to the first narrative, compassion and humanity are used in opposition to sanctity of life as an absolute that could lead to "*inhumane postures or cruelty*". As one opinion article puts it "*although compassion must be an absolute priority, it must not unconditionally have the last word, especially if it translates into a "condemnation to live" against any desire of the dying. […] When suffering resists all our efforts, that death precedes the intimate values of the dying and that he asks for it lucidly, euthanasia is not "a resignation of our human communities from suffering*". As such, humanity and compassion are needed to give a voice to those who are not heard by considering the *human* behind the sickness:

> *In fact, when one is inspired by compassion, it is easy to understand that certain ends of life are precisely inhumane and that simply "being alive" is not enough.* (Free translation)

> *You lose in compassion and humanity by speaking only of respect for life, not mentioning respect one owes to every living person at the end of life, to his values, dignity, conscience and finally freedom. In short, you lack credibility and probably even humanity. Sad.* (Free translation)

Rational-instrumental narrative 1: The lucrative Pandora's box

This narrative is mainly constructed around the *slippery slope and abuse* argument. Assisted suicide is presented as a path decision makers should not take because of the probable drifting,

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the unduly broadening of health professional's powers and consequent damages on the whole population. To back up this idea, a number of opinion articles cite *heard examples* of problems certain countries experienced. Pushed to the extreme, this position is supported by an argument on the "large number" of ill-intentioned people, "accomplices", who would take advantage of such a permissive law. This argument relates to *protecting the most deprived* where the sick or elderly is seen as inevitably bound to accept decisions about his/her life: "*The elderly, mentally or physically ill, are terrorized at the thought of the pressure they would face if they refuse to be euthanized, feeling like an 'unworthy burden' to have refused to ride the path*" (Free translation).

The slippery slope/abuse argument is also supported by fears of seeing a *decrease in palliative care services*. In fact, a number of articles assert that the underlying motive is to reduce services to alleviate the pressures on the health system.

> *With the shortage of resources in our health care system, which is more likely to deteriorate than improve, it may well be that in the future, life and death decisions will be dictated by financial considerations.* (Free translation)

> *The minister refuses to admit the budgetary advantage that the death of people who will not receive palliative care represents. Really, this question, I must tell you, it stuns me.* (Free translation)

> *The bill is a trap for Québec and will have an impact on the Canadian public and also globally. If our MPs are responsible, they will know, either by instinct or intelligence, that Bill 52 is a poisoned gift. This bill will seriously contaminate the notion and reality of palliative care.* (Free translation)

> *Quebec's proposed legislation on medically assisted death makes the following dangerous assertion: "End-of-life care means palliative care provided to persons at the end of their lives, including terminal palliative sedation and medical aid in dying." The bill, as proposed, unilaterally and without consultation with palliative-care specialists, redefines the meaning of palliative care. It proposes end-of-life care that is contrary to the internationally defined goals of palliative care. This is dangerous, as it will harm the provision of palliative-care services.*

Efforts to increase the number of efficient palliative services implemented is therefore preferred to the detriment of the adoption of the bill. This call for more services is also reinforced by a view that adopting any law that would make assisted suicide possible will change the essence of the medical practice:

These doctors-politicians are relaunching each other about the benefits and relief that "medical aid to die" will bring. They do not care about my opinion, my experience, nor do they care about the vast majority of my palliative care colleagues. They decided together that euthanasia, assisted suicide, medical aid to die are nothing but a "continuum of care". Sorry? To kill someone with a blow of a mortal dose would be a care in the same way as administering an antibiotic, diuretic, chemotherapy or surgery? What a mistake, not to say, what a lie! […] What is proposed is changing medicine, medical legislation, the code of ethics and my medical practice! (Free translation).

Rational-instrumental narrative 2: Liberating Death

The fourth narrative is also constructed through the *slippery slope/abuse* argument but as a cautionary statement against the artificial prolongation of life. In essence, the narrative decries the social construction of dying as something that needs to be remedied: "*It seems that death is perceived as a weakness, an error that an entire industry strives to correct, repel, and camouflage*". (Free translation). Medical progresses, rather than providing a panacea, are unduly transforming a natural life stage by "*prolonging the agony*":

> *Terminal sedation, used for otherwise uncontrollable pain relief until the person dies from "natural causes" is deemed morally acceptable. The cessation of hydration and food in terminally ill patients is also accepted. All know that the only way out is death. […] These are forms of euthanasia that do not dare to say their name.* (Free translation)

The slippery slope/abuse argument in complemented by the positive and negative *individual and social consequences* argument. On the positive side, the adoption of the bill is seen as a *liberating care* for all, including the patient (end of agony) and his/her family (end of feelings of helplessness). Society in general is also seen as benefiting from ending the *agony* which has financial and social costs. On the negative side, the slippery slope/abuse argument warns opponents about the danger of inducing an even more dramatic social situation: "*Exasperated people will help their loved ones die, often in horrible, unworthy, inhuman and tragic conditions. Others will commit suicide in solitude, in suffering. Unease among caregivers and health and social services institutions will continue to increase*" (Free translation).

The slippery slope and the individual and social arguments are strengthened by a third one, *decrease in palliative care services* also used in the third narrative. The decrease or insufficient

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provision of palliative care services is put forward as a situation that will not change in the near future. Based on this observation, the adoption of the bill is seen as even more *liberating*.

CONCLUSION

The four narratives that were drawn from the opinion articles offer an initial entry into the framing of the *Act respecting end-of-life-care*. The scope seems to go beyond the specific case of Quebec in that the nature of the issue is rather universal. To that effect, some arguments upon which the narratives were reconstructed, namely sanctity of life, dignity and autonomy, are similar to what other have found (Green-Pedersen, 2007; Haider-Markel & Joslyn, 2004; Haller & Ralph, 2001). However, our study does not align with others (Gailey, 2003) who found the legal frame to be an important one. Assertions such as to the "right to die" and "criminalization of families" for proponents, or "euthanasia is a crime", and the impossibility of "legal safeguards" for opponents, although present, were not dominant in the opinions articles.

What the narrative analysis brings to the framing discussion is a finer analysis of how and why the specific arguments are put forwards as well as how they build on each. Although the four narratives are illustrative of the four different positions on the issue (for and against the passing of the bill for moral reasons AND for and against the passing of the bill for rational-instrumental reasons), there is a high degree of proximity between the four narratives. On some aspects (dignity and slippery slope for instance), it can be stated that the issue is *fully framed*.

This analysis also contributes to enriching the work done to date on "morality policy" (Studlar et al., 2013; Burns, 2015; Knill, 2013; Heichel et al., 2013; Engeli et al., 2013; Mooney, 1999) and policy change. The mechanisms of change are distinctive for morality policy (Heichel et al., 2013; Snow, 2012). A variety of pressures may be implicated, with Heichel et al. (2013) differentiating between external "moral shocks" and "threshold policies", for instance, whereby a scandal might push an issue onto the public agenda as opposed to an issue that slowly becomes more noticeable until it passes a particular threshold (Heichel et al., 2013, p. 324). The Québec case seems to be both a moral and a threshold case as dramatic events stirred up the debate but discussions and consultations have spread over almost ten years. Further examination of different discourses (editorials, briefs tabled at the Special commission and interviews) are needed to expand and strengthen the analysis.

Finally, since policy change literature is often linked to agenda-setting, looking at how actors present an issue becomes a significant means of exploring policy change as a cognitive

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transformation. How particular frames moralize or demoralize an issue helps understanding how morality policy issues are produced.

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