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Assistance in dying across borders: How the transnational circulations of persons, terms and themes influence the construction of a public problem

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ABSTRACT

Assistance in dying has become a transnational issue debated and lawfully practiced in several jurisdictions around the world. This article focuses on persons, terms and themes that circulate from one context authorizing assistance in dying to another. Building on Joseph Gusfield's concepts of judgment, ownership and responsibility, we explore how national debates on assistance in dying draw on transnational circulations which are instrumental in the construction of this issue as a public problem. Adopting a transnational lens shows that local public problems of assistance in dying should not be apprehended in isolation nor compared as independent contexts.

Introduction

The French right-to-die advocate Jacqueline Jencquel, 74, publicly announced in 2018 her intention to seek assisted suicide in Switzerland in 2020, even though she has no medical condition that would lead to her death (Dellaire, 2018). David Goodall, a 104-year old Australian scientist, flew from his home in Western Australia to Switzerland to access assisted suicide with the help of *lifecircle* and Exit International, two right-to-die societies (Mucina et al., 2018). The French writer Anne Bert left France in 2017 to access euthanasia in Belgium following her diagnosis of amyotrophic lateral sclerosis (ALS) 2 years earlier (Rédaction JDD, 2017). All of these cases received international media attention. Phrases like medical assistance in dying (MAiD) and assisted dying used in public discourses in English are gaining traction internationally to designate both euthanasia and assisted suicide. Journalists and academics regularly discuss the numbers published by authorities in permissive jurisdictions.

Persons, terms and themes related to assistance in dying circulate from context to context in different manners. For the purpose of this paper, we define assistance in dying as including both provider-

administered and self-administered assistance in dying also called voluntary euthanasia and assisted suicide (Downie et al., 2021, this issue). Persons wanting to hasten their death travel to other jurisdictions where assistance in dying is allowed, advocates meet in different corners of the world to promote the so-called "right-to-die," and researchers and policy specialists look at assistance in dying practices in other jurisdictions. Terms like euthanasia, intolerable suffering, and death with dignity also circulate between national contexts. Some themes cross borders more easily than others, such as increasing numbers of assistance in dying requests and questions regarding access for minors, and for persons facing dementia, suffering from psychiatric illnesses, feeling that their life is "completed," or "tired of life."¹ These issues are anchored, to different degrees, in national legal systems, medical regulation, histories and cultures (Boivin et al., 2015; see also Kaufman, 2005 for the USA; Norwood, 2009 for the Netherlands; Voléry & Toupet, 2021, this issue for France). Nonetheless, people, terms and themes circulate.²

Assistance in dying has become a transnational issue debated in many countries and lawfully practiced in a few jurisdictions. As of October 2020,

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Switzerland, nine US states and the District of Columbia, the Netherlands, Belgium, Luxembourg, Colombia, Canada, the states of Victoria, and Western Australia in Australia, Germany and New Zealand all have authorized assistance in dying in one form or another. Assistance in dying is also known to be practiced informally and debated in other jurisdictions such as France, Spain, India, Japan, Uruguay, the US and other countries. As explained in the introduction to the special issue in which this article appears (Blouin & Pott, 2021, this issue), researchers have yet to theorize international comparisons regarding assistance in dying. Most often, assistance in dying contexts are presented as “models” that could be translated to other contexts or findings from one context are thought to be directly relevant to the understanding of the practice in other regional settings. It is often thought to be the case with policy and data from Oregon and the Netherlands that are well documented. The special issue suggests ways to problematize comparisons between contexts that present a wide variety of practices and discourses. This article attempts to do so by drawing attention to circulations between contexts. The transnational circulations between contexts are almost never problematized as such, although traces can be found in many books and articles, especially in the works based on assistance in dying as a new social movement (McInerney, 2000). Reflections on end-of-life care as a global issue also emerges in the work of Zaman et al. (2017) who interrogate the framing of debates and call for the acceptance of a plurality of local problems that might be solved through varying solutions.

This article focuses on what *connects* public debates between countries that authorize assistance in dying, on the persons, terms and themes that circulate from one context to the other and that contribute to the recognition of assistance in dying. First, we situate assistance in dying as a public problem building on Gusfield’s sociological perspective (Gusfield, 1981). We hypothesize that national debates on assistance in dying draw on the transnational³ circulations of persons, terms and themes and that those flows are instrumental in the construction of assistance in dying as a public problem. As Jouan (2017) has shown it regarding undocumented children’s right to education, international comparisons by various actors—researchers, advocates, media—play a key role in constructing public problems as those comparisons contribute to highlighting the question, raising public awareness and developing convincing arguments. Secondly, in three subsections, we respectively identify

traces of the circulations of persons, terms and themes between contexts, using Gusfield’s concepts to specify the contribution of each form of circulation to the construction of assistance in dying as a public problem.

To do so, we bring together various types of documents in English and French that show *traces* of those transnational circulations. We conducted a press review with Google News to identify prominent cases of persons who traveled to Switzerland to access assistance in dying, and reviewed public reports, academic articles, court decisions and institutional positions papers on assistance in dying from jurisdictions authorizing this practice. We identified traces of circulation between contexts in those different sources and we classified them in three categories: persons, terms and themes. We primarily focus on the effects of those circulations from the Canadian context but include examples from other areas. Our goal is not to measure the connections between national public debates nor to weigh the influence they have on each other. Also, we do not attempt to draw the full portrait of those circulations but only to provide examples. We wish to point to avenues that could be starting points to investigate further the relationships that connect national assistance in dying public problems.

Assistance in dying as a (transnational) public problem

McInerney (2000) problematizes assistance in dying through the lens of new social movements theories. She traces the origin of what she calls the “requested death” social movement that emerged at the turn of the nineteenth Century and succeeded in the 1990s through parliamentary and legislative responses. Before assistance in dying became a highly debated *public* problem, death was already considered a problem in relation with dying conditions in healthcare contexts. Kaufman (2005) explores the “problem of death, a problem that is manifested most visibly and dramatically by patients who have entered what [she] call[s] the gray zone at the threshold between life and death” (p. 1). In American society, Kaufman reports, this problem comes with “impossible choices” for patients, families and healthcare professionals. Patients and their families are compelled to make decisions regarding withholding or withdrawing treatments, do not resuscitate orders and medicalized options that may end an individual’s life. In the conversation about the “problem of death,” assistance in dying emerges

for some as a possible solution. Richards (2017) insists on considering the minority of people who choose assistance in dying as part of the “problem of death”. This minority “receives disproportionate media attention and evokes significant moral attention and public concern” (Richards, 2017, p. 348). Hintermeyer (2011) documented a similar disproportion in media coverage in France. As a consequence, assistance in dying does not only appear as a solution to the “problem of death”. Assistance in dying has become a public problem in and of itself that is now generally framed as a medical issue but that in fact predates the biomedicalization of the end of life (Lavi, 2005).⁴

Gusfield, who proposes a sociological approach to the study of public problems, distinguishes public problems from social problems. Social problems do not necessarily become matters of public interest and controversy as is the case with public problems. A public problem emerges when an issue is being construed as a matter of public concern requiring actions from official authorities (Gusfield, 1981, pp. 2–5). Assistance in dying often appears as a prominent issue in a few countries because certain conditions allowed it to be seen for some as a solution to a variety of individual motivations regarding one’s end of life—such as pain, feeling of being a burden, loss of control, etc.—and to address the problem of unsupervised, unsafe and illegal practices of assistance in dying (Emanuel et al., 2016; Magnusson, 2004). But the status of assistance in dying as a public problem is contested. For some, the legalization of assistance in dying is the problem while for others the problem is its prohibition. This contested status is part of what makes assistance in dying a public problem (Gusfield, 1981, p. 10).

Gusfield has not worked on public problems as transnational issues. Different approaches look at how a question gains international relevance. The diffusionist approach considers that a question arises in a given context and then circulates toward others if certain conditions are met (Strang & Meyer, 1993). The functionalist/structuralist approach looks at how similar questions arise in different contexts at the same time for reasons that might be different (see Voléry & Toupet, 2021, this issue). In this article, we do not side with one approach or the other. This article argues that attention should be paid to transnational circulations in order to better understand the constitution of assistance in dying as a public problem. It is a first exploration of the significance of transnational circulations. Even if assistance in dying has become a transnational interpretative framework

that resonates and is used in a variety of contexts, it does not mean that it is accepted as it can be perceived as “foreign” or “international” (i.e. “American” or “Euroamerican”) such as in Japan (Long, 2004, pp. 916–917).

Transnational circulations of persons, terms and themes

In this article, we present circulations of persons, terms and themes in three different sections for clarity, but these three categories overlap with each other as evoked in examples below. Each category of circulations respectively contributes to the construction of three dimensions of public problems identified by Gusfield (1981, pp. 9–10): judgment, ownership, and responsibility.

Judgments and the circulation of persons

Even though a public problem can become transnational without people having to physically move, the circulations of three categories of persons—persons seeking assistance in dying, experts, and advocates—have contributed to shaping assistance in dying as a transnational public problem. The circulations of these “moral entrepreneurs” (Becker, 1963/1997) inform the *judgments* the public and institutions can make toward the assistance in dying questions. According to Gusfield (1981, pp. 9–10), public problems rely on cognitive and moral judgments, beliefs about a “world of fact” that is posited and informs the moral conviction that something can and should be changed.

Persons seeking assistance in dying. Persons seeking assistance in dying in countries where this practice is illegal, or the access restrictive, travel to jurisdictions where the practice is more liberal.⁵ Those circulations posit the “world of facts” accessible to the public and institutions, and inform their judgment.

First, those circulations demonstrate that the public problem of assistance in dying is about something that is alterable: the dying process can be changed. Some jurisdictions allow assistance in dying and even citizens of jurisdictions where it is forbidden can have access to it. Switzerland is the best-known example of a jurisdiction allowing persons without local residency to have access to assistance in dying. Switzerland functions like a “hub” (“*plaque tournante*” in French) for the public problem of assistance in dying (Blouin, 2018). Persons go to Switzerland to access assisted suicide which has the effect of sending back substance

for debate to their home countries. Switzerland does not have a monopoly on the circulation of persons seeking assistance in dying. The Netherlands, Belgium and Luxembourg also have permissive legislation regarding assistance in dying and no residency requirement. Their procedures require that two physicians determine whether requesters made a voluntary, considered request and suffer unbearably, which is interpreted to imply that physicians must have known the patient for some time. This fact prevents the development of important flows of persons traveling to these countries to access assistance in dying. Moreover, assisting nonresidents remains somewhat controversial in public debates and among physicians (regarding Belgium, see Hamarat, 2020). This reluctance to assist nonresidents suggests that the exercise of biopower and thanatopower—the set of policies and norms for maximizing and interrupting life—has historically been strongly embedded in national medical regulations (see Voléry & Toupet, 2021, this issue). Nonetheless, there are examples of persons from neighboring countries who received access to this procedure in Belgium (Hamarat, 2020) and in Luxembourg.⁶ Circulations of persons seeking assistance in dying also exist within the United States, where each state authorizing assistance in dying requires the individual to confirm residency prior to beginning the process.⁷ For example, Brittany Maynard moved from California to Oregon in 2014 in order to have access to assisted dying after being diagnosed with a brain cancer.⁸ Maynard's story was used to promote the assisted dying legislation that went into effect in California in 2015. Those circulations show to the public that assistance in dying is not merely an idea but also a practice that involves fellow citizens in contexts where it is not allowed.⁹

Secondly, those circulations show to the public that those persons' suffering is unbearable or that their wish to die is strong enough that they are ready to die far from their loved ones. Several nonresidents who accessed assisted suicide in Switzerland have received important media coverage in their home countries—Reginald Crew in 2003 in the United Kingdom, Ernst-Karl Aschmoneit in Germany in 2003, Manon Brunelle in Quebec in 2004, Edward and Joan Downes in 2009 also in the United Kingdom, DJ Fabo in Italy in 2017, Jacqueline Jencquel in France in 2018, Richard Selley again in the United Kingdom in 2019 –, or even internationally, such as in the aforementioned case of David Goodall. People going to Switzerland to access assisted suicide predominantly come from the following countries: Germany (45%)¹⁰,

United Kingdom (15%), France (12%), Italy (5%), USA (4%), Canada and Austria (2%) (Dignitas, 2019). The circulations of persons are primarily from high-income countries relatively close to Switzerland geographically. In this process, some persons generate media attention, depending on the case. Moreover, the loved ones accompanying these persons to Switzerland sometimes testify publicly about this process when they return home. For example, Elaine Selley, Richard Selley's wife, said to the British Broadcasting Corporation (BBC, 2019a): “But for Richard and for his pain and his distress in that moment in time, which was far worse than it was at home, we knew he was doing the right thing for him.” She added: “He really had had enough and wanted out of it and although we didn't want to lose him, didn't want it to happen and it was scary, it was the right thing for him.” The media coverage of those persons' testimonies insists on their determination to end their suffering and on how assistance in dying can be a positive experience besides having to travel away from their home country. Those experiences would hardly be possible nor available to the public of more restrictive jurisdictions if it were not of those transnational circulations.

Thirdly, departures of persons to access assistance in dying abroad engender public controversies through which the public and institutions are expected to take a stance. Gauthier et al. (2015) have shown that those circulations contributed to debates on the “liberalisation of the prosecution practice in the UK following assistance in suicide” and “gave rise [in Germany] to a draft law at the end of 2012, in which commercial suicide assistance would be punishable” (pp. 5–6). Prominent cases play a determinant role in the evolution of legal frameworks in various contexts. In Canada, Kay Carter, whose daughter and son-in-law were among the plaintiffs in the Supreme Court of Canada decision in *Carter v. Canada* which decriminalized assistance in dying across the country in 2016, used the services of Dignitas. Her daughter, Lee, told the *Vancouver Sun* that her mother “wants people in Canada to talk about it. She believes it's a choice Canadians should have” (Todd, 2015). A similar story unfolded in Italy where the top court ruled that assisting a death is not always a crime if certain conditions are met and requested the intervention of the parliament (BBC, 2019b). The court ruled on the case of Marco Cappato, who helped DJ Fabo to access assistance in dying in Switzerland. He was acquitted following this decision. In Quebec, Canada, a documentary film aired in 2004 showed, for the first time

to the public, the assisted death of a Quebec resident who flew to Switzerland. This documentary launched a public debate to legalize assistance in dying in the province (Blouin, 2018). The intention of the film makers was to initiate this conversation in Quebec. In the film, the requester says: “I want it to be something that’s a beacon of a possible reality”. Her testimony was meant to demonstrate and justify the merits of assistance in dying that was unlawful in Quebec at the time.

Assistance in dying experts. Another category of actors with an interest in assistance in dying in other jurisdictions is composed of researchers, healthcare professionals, ethicists, healthcare policy analysts and legislators. They often examine the assistance in dying regime adopted by their own country but also look at other regimes that they sometimes contrast with the one prevailing in their jurisdiction. For example, American researchers studied decisions made by Dutch regional euthanasia review committees (Miller & Kim, 2017), Canadian and American researchers studied assisted suicide by oxygen deprivation in Switzerland (Ogden et al., 2010), American and Dutch researchers studied evidence concerning the impact of physician-assisted dying on patients in “vulnerable” groups in Oregon and the Netherlands (Battin et al., 2007), and other researchers from different countries compared national models of assistance in dying (Steck et al., 2013, this issue). Experts also have international networks. Since 2014, researchers, healthcare professionals and advocates have met every few years at the International Conferences on End of Life Law, Ethics, Policy, and Practice (ICEL) held in countries where assistance in dying is now practiced. Assistance in dying terms have changed over time in ICEL calls for papers in different countries: euthanasia and assisted suicide (Australia, 2014), medical assistance in dying (euthanasia and assisted suicide) (Canada, 2017)¹¹, and medical assistance in dying/euthanasia (Belgium, 2019). Through their studies and networks, researchers contribute to the circulation of terms and themes.

International researchers provide much of the evidence used in court cases, public reports and media accounts, thus constituting the “facts of the matter,” in countries that have considered authorizing assistance in dying (Canada, Australia) or that are considering expanding access (Canada) (Karsoho et al., 2017, p. 3). For instance, the *Carter v. Canada* (Supreme Court of British Columbia, 2012) trial decision that found the blanket prohibition on assistance

in dying in Canada unconstitutional, relied heavily on testimonies of experts and research from more permissive jurisdictions concluding that facts had changed since the 1993 Supreme Court decision in *Rodriguez* (Supreme Court of Canada, 1993). The existence of evidence from other jurisdictions, unavailable at the time, notably about the efficacy of safeguards, played a key role in the court’s reasons to reconsider the 1993 decision (par. 999–1001). In Quebec, members of the National Assembly (MNAs) traveled to Belgium and the Netherlands to obtain information on the implementation of assistance in dying legislations: “However, we could not find literature to validate certain powerful but contradictory arguments on the experiences of European countries where euthanasia is legal. For this reason, we decided to go to Europe to see for ourselves. This mission was a very important step in the reflection process” to recommend the legalization of assistance in dying in Quebec (Select Committee on Dying with Dignity, 2012, p. 53). During this mission, MNAs met with several experts from France, Belgium and the Netherlands. Finally, some studies conducted in permissive jurisdictions get media coverage in other contexts. In Quebec, a study comparing data from Oregon and the Netherlands by Battin et al. (2007), received media attention to negate a “slippery slope” argument against assisted dying (*La Presse*, 2007).

These examples highlight the impact of transnational expert networks in the constitution of national assistance in dying public problems and, more broadly, in the constitution of assistance in dying as a transnational public problem. Experts constitute and share the facts on which the public and institutions can rely to form judgments. They also illustrate how research plays a role in backing claims on this controversial topic.

Assistance in dying advocates. Advocates are a third category of actors instrumental in the constitution of assistance in dying as a transnational public problem. The right-to-die social movement became politically active in the 1930s in the United States and the United Kingdom (Judd & Seale, 2011). The World Federation of Right to Die Societies was founded in 1980 and now consists of 51 organizations from 26 countries.¹² During the biennial conferences of the World Federation, advocates from around the world debate different questions, such as “Is assisted dying a human right?” (Dying with Dignity South Africa, 2018), and present the evolutions of the assistance in dying issue in their country. These meetings provide inspiration

for national organizations that learn from what is done elsewhere. For example, the founders of the right-to-die society EXIT A.D.M.D. Suisse romande, active in the French-speaking region of Switzerland, invited a representative of the British association to the meeting during which the society was created in 1982. The British representative explained the functioning of his society to the EXIT founding members (EXIT A.D.M.D. Suisse romande, 2007, p. 8). In Canada, an advocate for medical assistance in dying explained to Blouin during his ethnographic study on assistance in dying how the World Federation meetings contributed to her training as a right-to-die advocate and how the many contacts she keeps with other advocates in France and Switzerland helped her gain confidence. “We are not all alone,” she said. She also used the French right-to-die societies’ by-law as a basis to establish its own society in Canada. The circulations of advocates contribute to empowering the movement by making successes known and sharing *modus operandi*. Those circulations allow advocates to share views and support their perspectives.

The circulations of persons seeking assistance in dying abroad, experts and advocates empower actors to promote a different way of viewing the dying process. These circulations give credibility to the claims of those actors who suggest that altering the dying process is possible and justified.

Ownership and the circulation of terminology

Descriptions, definitions and names related to the public problem of assistance in dying are controversial. The terms used to talk about it reflect the tensions between competing perspectives. Assistance in dying can be associated to murder, suicide, healthcare, death with dignity, according to one’s moral stance, circumstances, or to the name of the law (Vamos, 2012). Paying attention to how certain terms circulate, or not, supports a better understanding of who owns the public problem of assistance in dying and how it functions on the transnational scale. Gusfield (1981) states that “in the arena of public opinion and debate all groups do not have equal power, influence, and authority to define the reality of the problem” (p. 10). One might ask who can make credible assertions about the issue and who has the authority to propose descriptions and definitions of the problem. In relation to assistance in dying, physicians and medical associations are prominent voices in the public arena that shape and influence the parameters of the public problem. However, they do not have a monopoly over the problem. Nonetheless, it could be argued that the

medical profession has a great share of “ownership” (Gusfield, 1981, pp. 13–16), as other actors usually debate the issue based on medical terms (Gandsman, 2018). The actors owning the public problem can also change over time. In Switzerland, for instance, right-to-die societies and their advocates emerged in the 1980s as the prominent actors of the public problem. They ascertained their ownership of the public problem before other actors, such as medical institutions, gained an interest in the problem in the beginning of the 21st century (Beldi, 2008).

Official terms used around the world. The Netherlands, Belgium and Luxembourg were among the first countries to legalize assistance in dying. The laws of these countries use the terms euthanasia and/or assisted suicide. These terms have circulated worldwide and been used in public discussions in various contexts. However, no other countries have embedded these terms in their legislation and public policies even though they may have been influenced by their assisted dying model. For instance, the parliamentary committee charged with studying the question of dying with dignity in the province of Quebec in Canada retained many features of the Dutch and Belgian models to craft its own regime (Select Committee on Dying With Dignity, 2012). But it used the phrase “medical aid in dying,” likely drawing on terms already in circulation in reports and academic literature (assisted dying, physician-assisted dying, aid in dying, etc.). Colombia might be the only exception to this trend to using different terms. The Constitutional Court of Colombia (2014) recognized euthanasia as a means to achieve the right to die with dignity, explicitly drawing on experiences from the Netherlands, Belgium and the US to justify its decision. In Switzerland, a country that has been legally tolerating assisted suicide since 1942, neither its model nor the term “assisted suicide” circulated. In the US, jurisdictions that authorize self-administered assistance in dying use terms in legislation that include “end of life option,” “death with dignity,” and “our care, our choice.” In the US, the term suicide is not used in any of the laws, except to mention that assistance in dying does not legally constitute “suicide.” The expression “physician-assisted suicide” was even stripped of governmental websites in 2006 in Oregon and replaced by the title of the law, Death with Dignity (Tucker & Steele, 2007, p. 315). Terms that suggest option, dignity, and care appears to be more globally acceptable than euthanasia and assisted suicide. It is likely that the terms euthanasia and assisted

suicide did not circulate in policy documents because of the negative historical connotation associated with euthanasia in Nazi Germany and of the association of suicide with depression and mental illness (Boer, 2003, pp. 229–230; Karsoho et al., 2017, pp. 6–7).

Official terms that resonate. Examining jurisdictions that have recently authorized assistance in dying allows us to observe and understand which official terms resonate internationally. In the province of Quebec (Canada) the select committee charged with studying the question of dying with dignity recommended to legalize euthanasia but under a different name because the term used in the Netherlands and Belgium was considered “emotionally charged, and not everyone agrees on its use” (Select Committee on Dying With Dignity, 2012, p. 76). The suggestion, adopted by parliament, was to use the phrase “medical aid in dying”. The stated goal was to emphasize the value of support. The word “medical” was included to specify the nature of the support that involves physicians and caregivers. The committee also decided not to recommend the legalization of assisted suicide to veer from the idea of suicide (Select Committee on Dying With Dignity, 2012, p. 79). Quebec adapted the Dutch and Belgium models and rebranded them. At the federal level in Canada, the phrase “physician-assisted dying” has been used in the *Carter* decision and in various policy reports. The legislation that was passed uses the phrase “medical assistance in dying” to include nurse practitioners who are also allowed to provide this intervention. In 2019, the US state of New Jersey adopted the “Aid in Dying for the Terminally Ill Act” and Maine adopted the “Death with Dignity Act.” In Hawaii, the phrase “medical aid in dying” was used in the title of one version of proposed legislation that was finally passed in 2018 under the title “Our Care, Our Choice Act” (Hawaii State Department of Health, 2018). However, “medical aid in dying” is often used by Hawaii government websites, researchers and journalists.¹³ In the state of Victoria, Australia, the Ministerial Advisory Panel on Voluntary Assisted Dying (2017) chose to use “voluntary assisted dying” (VAD) to avoid negative connotations associated to euthanasia and suicide and to emphasize that “this is a decision initiated by a person who is suffering and who takes responsibility for the decision” (p. 8). Despite international influence, the parliamentary report proposed a framework reflecting “the values and culture unique to a particular jurisdiction” (Parliament of Victoria, 2016, p. 217).

The committee compared the models of the US and the Netherlands to show the importance of culture and values. To illustrate this claim, the committee gives, as an example, the important value of self-determination in the US that does not require the physician to be present when the patient self-administers the medication. The nature of the patient-doctor relationship in the Netherlands requires a physician presence. Like Quebec, Victoria imported some technical features of other models but felt the need to rename the practice to better reflect the local context.

In sum, many official terms do not circulate well because they are constantly needing to adapt to local contexts and language differences. However, for the most part, the phrases “assisted dying,” “aid in dying” and “assistance in dying” resonate globally because they are less controversial than euthanasia and assisted suicide. The inclusion of “medical” to “assistance in dying” in Canada formed the acronym MAiD that is gaining popularity throughout North America, appearing to replace “physician-assisted dying”. More research is needed to understand where, how and why this phrase has been trending and how long it will last. One possible explanation is that adding “medical” validates and reinforces the medical ownership of the practice and of the public problem, and thus confirms that it is a *professional* practice that responds to medical standards, regulations, and guidelines. For example, the right-to-die organization *Compassion & Choices* has a section of its website titled *Medical Aid in Dying is Not Assisted Suicide, Suicide or Euthanasia*. It adds that “Medical aid in dying is a safe and trusted medical practice...” (Compassion & Choices, n. d. b).¹⁴ The Swiss model differs as it does not formally require the involvement of healthcare professionals. If they are involved, it is primarily out of a personal commitment instead of a professional one. Lastly, legislation around the world adopts vocabulary put forward by most proponents of assistance in dying. The use of those terms that circulate well tends to strengthen the share of ownership of the public problem held by medical professionals and right-to-die advocates.

Responsibility and the circulation of themes

Different themes in public discourses account for the existence of the public problem of assistance in dying, such as sanctity of life, suffering, slippery slope and autonomy (Boer, 2007). Certain forms of those themes circulate internationally. Defining assistance in dying as a *medical* public problem comes with the rise of

suffering as a dominant theme in the understanding of this question (Kious & Battin, 2019). Suffering has the potential to be the locus of the public problem. It interrogates the causal responsibility (what is this suffering that makes people request assistance in dying?) and the political responsibility (what should be done about it?). It functions as a “master frame” that is flexible enough to be adopted by various actors, movements and jurisdictions because it has a broad interpretative scope (Benford, 2013). Gusfield (1981) addresses causal and political responsibilities in his exploration of public problems (pp. 13–16). Causal responsibility refers to the explanation for the existence of a problem. One might ask if assistance in dying is a public problem because there is poor care for those suffering at the end of life, or because not all suffering can be alleviated by palliative care. Alternatively, one may ask if this public problem is a result of a rampant “culture of death”¹⁵ or of people wanting to die on their own terms. Political responsibility points to who is charged with solving the problem. Do people look toward government, the medical profession, associations, courts? We suggest that themes around suffering circulate well because they allow a discussion of both causal responsibility and political responsibility.

The theme of suffering appears in public debates, policy, legislation and research in Switzerland, the Netherlands, Belgium, Luxembourg, Colombia, Canada and Australia. In the US, suffering is not part of the formal conditions required to access assistance in dying in the states that authorize this practice, but the theme of suffering is nonetheless recurrent in public debates (Kious & Battin, 2019, pp. 30–31). Phrases like “intolerable suffering,” “tiredness of living” and “completed life” are some of the categories used to talk about suffering in the various jurisdictions allowing assistance in dying. In the Netherlands, “intolerable and lasting suffering” constitutes the main justification in policy documents for the involvement of physicians in assistance in dying (Royal Dutch Medical Association [KNMG], 2011). This theme is also used in Belgium and Luxembourg policy documents and legislations. In 2018, the Swiss Academy of Medical Sciences (SAMS) modified its guidelines on the *Management of Dying and Death* to recommend that physicians consider intolerable suffering instead of the end of life when assessing requests for assisted suicide. This change was made at the same time that the SAMS abandoned the idea that assistance in dying was not part of the medical activity, stating instead that assisted suicide is a controversial act and that

every physician must decide for themselves if it corresponds to the goal of medicine. This move allows the SAMS to be in line with right-to-die societies and physicians that were already granting requests based on the criterion of intolerable suffering for people not at the end of life. If the goal of medicine is to alleviate suffering (Cassell, 1991), and the cause of these requests is understood to be due to suffering then the involvement of physicians is deemed justifiable.

Transnational circulations challenge the attribution of responsibility for the public problem. First, persons like Manon Brunelle, who traveled to Switzerland to access assisted suicide before medical assistance in dying was legal in Quebec, called for medical professionals to take their responsibility and offer assistance in dying to prevent suffering people to have to go abroad to be assisted by volunteers who are not necessarily medical professionals. One year after the implementation of medical assistance in dying in the province, the Collège des Médecins du Québec (2017), the regulator of the medical profession in Quebec, suggested in a blog post that other options than the involvement of physicians, such as the Swiss model, should be considered if assistance in dying is to be performed outside of a healthcare logic. The reference to the Swiss model serves to establish the boundaries of the medical responsibility and practice that are limited to situations of suffering linked to a medical condition. Secondly, a controversial variation on the theme of suffering is emerging: some people could get access to assistance in dying when they are “tired of living,” when they deem their life to be “completed” or without their suffering being somewhat connected to a medical condition. The Netherlands and Belgium appear to be the first countries to debate these questions. In 2016, the Dutch Liberal party ‘Democrats 66’ drafted a bill that would give access to assistance in dying to elderly feeling that their life is “completed” (van Wijngaarden et al., 2018). In 2017, the KNMG took a position arguing that physicians would still be involved in euthanasia if such a bill was passed notably because patients would need to be assessed for decision-making capacity (KNMG, 2017). A report by the Belgian Advisory Committee on Bioethics (2017) describes that the Dutch academic and gray literature have been debating about “completed life” and “tiredness of living” for twenty years. Neither of the two countries currently authorize assistance in dying on the sole basis that a person is “tired of living”. The question of access to assistance in dying for people “tired of living” is also being studied by EXIT Deutsche Schweiz, the largest right-to-die society in

Switzerland (Covo, 2018). This theme has also emerged in Canada in a court decision in which the Belgian and Dutch cases either serve as examples of potential abuses if Canada were to broaden eligibility criteria or as evidence that safeguards can work. In this decision, the court sides with the latter position and found risks for vulnerable populations are “theoretical” (par. 459). However, the Superior Court of Quebec (2019, par. 427) stresses that foreign evidence loses relevance as more local data are becoming available.

Experiences from some jurisdictions regarding suffering in relation to assistance in dying influence public debates in other contexts and interrogate the responsibility of the state and the medical profession in the regulation of assistance in dying. Transnational circulations provide frames, language and evidence to approach local questions that are addressed at the national level.

Conclusion

Transnational circulations of persons, terms and themes between contexts contribute to the formation of moral judgments about assistance in dying, to the professional definition of the public problem, and to the attribution of causal and political responsibilities. First, the existence of permissive jurisdictions authorizes and legitimizes the claim that assistance in dying is among the reasonable options available to address the “problem of death”. Circulations of persons—requesters, experts, and advocates—contribute to showing that this possibility is real and that it has some moral appeal. Secondly, the adoption of terms that are not too controversial or morally charged, such as assisted dying and medical assistance in dying, eases their circulation. The circulations of terms that support the recognition of assistance in dying tend to affirm a medical definition of the public problem and the perspective of advocates in favor of this practice. Thirdly, the assistance in dying problem relies on general themes that function in various contexts. The theme of suffering can circulate between contexts as different as the Netherlands, Switzerland and Canada because it expresses a general concern that is vague enough to be interpreted in relation with various local contexts and specific enough to bridge causal and political responsibilities. Its usage in a given context and the ideas it evokes in other contexts serve to delimit the responsibility of the state and the medical profession. Transnational spaces do not replace national contexts in which those circulations are interpreted.¹⁶ The public problem can only be addressed at the national level

because states have the authority to change healthcare and criminal legislations that prohibit, tolerate and regulate the practice.¹⁷ Transnational circulations, nonetheless, force comparisons between contexts by the actors involved who have to justify their judgments, the ownership and definition of the problem, and the attribution of responsibility based on other configurations. Adopting a transnational lens shows that local public problems of assistance in dying should not be apprehended in isolation nor compared as independent contexts. Comparative research on assistance in dying needs to better reflect those circulations that hardly surface when contexts are simply juxtaposed.

Notes

1. Phrases like “tired of living” and “completed life” are used in public debates to designate the experience of persons presenting a wish for hasten death without suffering from a medical condition, notably elderly feeling that their life is no longer worth living (van Wijngaarden et al., 2015).
2. “Circulation,” or the verb “circulate,” are terms widely used in the social sciences and humanities literature to designate “any sort of movement, transmission, or passage” of goods, people and ideas (Gänger, 2017, p. 303). Gänger criticizes the use of the “circulation” terminology in the discipline of global history because it can oftentimes be misleading by suggesting the movements described are effortless and that they are without “motor or force”. However, she recognizes that this concept might be useful for the modern era characterized by “fluidity” at the global scale (Gänger, 2017, p. 316). In this article, we will use the “circulation” terminology to convey the idea that the transnational phenomena that we pinpoint are polymorphous, sometimes taking the form of media diffusion, of travel by plane, of citation practices, and many others.
3. We use the term “transnational” in a broad sense: “The *transnational* characterizes a space functioning beyond national borders without being organized by an international or regional body” (Sapiro et al., 2018, p. 8 [our translation from French]).
4. Trials in different countries played an important role in making personal “impossible choices” a matter of public concern in national contexts (Pierson, 1998).
5. This process is often called “suicide tourism” or “death tourism”. For critiques of the “tourism” terminology, see Haesen (2018).
6. In 2015–2016, there were seven arrangements for the end of life (*dispositions de fin de vie*) registered by non-residents in Luxembourg (Commission nationale de contrôle et d'évaluation..., 2016, p. 10). Those arrangements are advance directives for assistance in dying.
7. See Death with Dignity National Center (n.d.).
8. See Compassion and Choices (n.d. a).

9. At the national level, McNerney (2000, p. 142) shows how the reportedly 130 people assisted to die by Kevorkian in the United States contributed to make “alternative modes of behavior accessible to wide audiences” (citing Gusfield, 1994, p. 74).
10. The Swiss right-to-die society Dignitas has an address in Germany.
11. “Medical assistance in dying” has been the official phrase used in Canada since 2016.
12. See <https://www.worldtrtd.net/>
13. For example, the Hawaiian government’s Frequently Asked Questions document for its residents labels the required medical prescription “medical aid in dying (MAID) prescription” (Hawaii Department of Health, 2019).
14. In the United States, “medical aid in dying” only designates the self-administration of a lethal medication, contrarily to Canada where it can designate both provider-administered assistance in dying and/or the self-administration.
15. The phrase “culture of death” is for example used in John Paul II’s *Evangelium Vitae* (1995, par. 12).
16. The media plays a central role in the structure of the assistance in dying problem on national stages (Crumley et al., 2019; Hintermeyer, 2011), but its role in the trans-nationalization of the public problem remains to be explored.
17. International courts are a counter-example to this statement. The European Court of Human Rights rendered several decisions regarding the end of life (European Court of Human Rights, 2019).

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