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Assistance in dying: Conditions for international comparison

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ABSTRACT

This special issue of *Death Studies* interrogates conditions for conducting international comparisons of assistance in dying regimes, and of related discourses and practices. To do so, it provides comparative social sciences and humanities perspectives on assistance in dying. In this editorial introduction, we first trace the origin of this special issue to the symposium held in 2018 in Lausanne, Switzerland. We then offer a short exploration of how assistance in dying regimes have been compared in the literature. Finally, we identify key conditions for conducting international comparisons of assistance in dying based on the articles presented in this issue of *Death Studies*.

Introduction

This special issue of *Death Studies* interrogates conditions for conducting international comparisons of assistance in dying regimes, and of related discourses and practices. To do so, it provides comparative social sciences and humanities perspectives on assistance in dying. An encounter between researchers from different jurisdictions and disciplinary backgrounds at a symposium that we organized in 2018 in Lausanne, Switzerland led to the realization that assistance in dying is *empirically embedded* in broader political, cultural, religious, institutional, and economical contexts that are seldom discussed, analyzed (Howarth & Jefferys, 1996, p. 377), and taken into account in comparisons of assistance in dying. In the literature on assistance in dying, interest in international comparisons is relatively new outside of public policy studies. Indeed, to our knowledge, this issue of *Death Studies* represents one of the first attempts to tackle the challenge of international comparison based on qualitative and fieldwork studies on assistance in dying. This international and interdisciplinary experience of contrasting various regimes of assistance in dying from a social sciences and humanities perspective generates theoretical and methodological questions and challenges that pave the way for a new research agenda.

Terms used to talk about assistance in dying—such as assisted suicide, death with dignity, euthanasia, and medical assistance in dying—are not standardized, and designate various practices in different jurisdictions. Likewise, eligibility criteria for those practices vary from one jurisdiction to another. Assistance in dying regimes are thus formulated as responses to a range of policy and moral objectives: alleviating pain and suffering at the end of life, upholding personal autonomy, reducing harm, socializing death, clarifying the role and ethical obligations of physicians, and so on. Actors involved in the provision and regulation of assistance in dying are numerous (e.g., coroners, ethicists, lawyers, nurses, pharmacists, physicians, police officers, politicians, psychologists, social workers, volunteers, among others), and vary from context to context. Institutions, such as associations, the justice system, legislative bodies, the media, the police, professions, religions, and review committees also participate in assistance in dying. Moreover, terms, information, and actors circulate between contexts, which adds a layer of complexity to the analysis of assistance in dying. Experience with assistance in dying also varies greatly between jurisdictions, with legalization occurring from as early as 1942 in Switzerland to as recently as 2019 in the state of Maine in the United States—although the year of

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legalization says nothing about the state of the practice at a given time. The composite nature of assistance in dying requires theoretical frameworks to grasp the intersections of different analytical levels—institutions, practice, public debate, regions, transnational circulations (Giraud, 2012; Ragin, 2007)—that constitute specific assistance in dying regimes (Blouin, 2020, 2021). This is true not only with reference to assistance in dying in specific jurisdictions or contexts but also—and to an even greater extent—when using a comparative international perspective.

In this editorial introduction, we first trace the origin of this special issue to the 2018 symposium in Lausanne. We then offer a short exploration of how assistance in dying regimes have been compared in the literature. Finally, we identify key conditions for the international comparison of assistance in dying based on the articles presented in this issue of *Death Studies*.

An international and interdisciplinary symposium: the challenges of problematizing assistance in dying collectively

The initial idea of bringing together researchers from different jurisdictions and backgrounds came from the observation that the specificity of the Swiss regime of assisted suicide has often been poorly understood in the academic literature. Switzerland is the only jurisdiction with a civil regime of assistance in dying that relies on volunteers from right-to-die societies, who are not necessarily health care professionals (Berthod et al., 2020; Gamondi et al., 2018). In the first half of the twentieth century, the concern of the legislator permitting assisted suicide was related not to individual health considerations but rather to reasons pertaining to honor or romance (Hurst & Mauron, 2003, pp. 271). According to Mauron (2010, pp. 153–154), the history of assisted suicide in Switzerland is of conceptual interest as it exposes the question of voluntary death as lying outside the exclusive domain of health. The Swiss regime allows us to go beyond the medical discourse on assistance in dying and provides room for nonclinical disciplines to advance research on assistance in dying as a social phenomenon, which is reflected in some of the articles in this issue.

The 2018 symposium, funded by the Swiss National Science Foundation, the Pallium Foundation, and the Health Promotion Fund of the University of Applied Sciences and Arts Western Switzerland (HES-SO), brought together 16 researchers from Belgium, Canada, France, the Netherlands, Switzerland, the

United Kingdom, and the United States, and from disciplines such as anthropology, bioethics, health policy, history, law, nursing, social work, and sociology. During the symposium's five days, researchers were invited to present their research interests and to reflect on specific topics, such as terminology and conceptual distinctions, assistance in dying trajectories, and social norms around assistance in dying. On the last day of the workshop the group developed the theme of conditions for conducting international comparisons of assistance in dying, and decided to explore it from the contexts in which the various researchers live, based on data they had already gathered or by proposing original analytical perspectives, which led to this special issue.

The international and interdisciplinary nature of the symposium proved to be challenging for a number of reasons. First, the working languages of the participants were Dutch, English, French, and Italian. Interestingly, it was precisely this linguistic plurality that allowed some subtleties of the terminology concerning assistance in dying used in each context to surface. The comparative glossary that follows this introduction illustrates the difficulty inherent in directly translating the legal terms used to designate assistance in dying in different jurisdictions (Downie et al., 2021, in this issue).

Second, the interdisciplinary nature of the researchers proved challenging, as we were not always able to agree on the terms of the conversation. Research interests, concepts, and methodological approaches appeared to differ considerably, sometimes to the point that it was difficult to understand each other. Over time, there have been changes in terms of which disciplines are concerned with assistance in dying. Shai Lavi (2005, pp. 4) showed how the question of dying, while once mainly considered part of the religious domain, was then medicalized and is now understood in terms of law and public policy. The social sciences and humanities have the conceptual and methodological resources to grasp this shift, to show that assistance in dying can be considered in terms other than those of medicine and public policy. The journal issue attempts to put these various disciplinary voices into perspective.

Third, even when we discussed concrete practices and assistance in dying trajectories, international comparisons were far from clear-cut. What are the boundaries of the practices at stake? What are the different “moments” constituting assistance in dying trajectories? How do these moments differ from context to context? Depending on the theoretical frameworks

used, or the empirical interest of the researcher, assistance in dying can be construed in various ways.

These productive linguistic, interdisciplinary, and comparative tensions led us to identify a lack of problematization and theorization in the international comparison of assistance in dying regimes. Assistance in dying regimes are most often presented alongside one another, without much context. Likewise, data, practices, and discourses are straightforwardly compared. For example, the terms “euthanasia” and “assisted suicide” are taken to refer to similar practices in different contexts; the meaning of the practice in a given jurisdiction is rarely accounted for; and how a practice is embedded (or not) in broader political, cultural, religious, institutional, and economic contexts is not discussed or analyzed. Data from well-documented assistance in dying regimes, such as that in the Netherlands, are also regularly transposed to other contexts without sufficient justifications as to the relevance of those findings to other contexts. We hope that this special issue will generate additional comparative research projects that will contribute to the international conversation on assistance in dying.

Assistance in dying from a comparative perspective

In order to compare, one has to “construct the comparable” (*construire du comparable*), to use Marcel Detienne’s (2000) phrase. To construct the comparable, theories and clearly defined concepts are necessary to situate what is being studied; data do not speak of themselves, let alone compare themselves.

Defining assistance in dying

The first required step for this special issue is to define what we understand by assistance in dying. Like other authors (e.g., Bosshard et al., 2002), we opted to use the phrase “assistance in dying” to designate practices that are commonly referred to as “euthanasia” and “assisted suicide,” because those terms are not self-evident—as shown by the comparative glossary that follows this introduction—and also because those practices exist on a continuum. This decision is intended to privilege a more descriptive term and to avoid, to the greatest extent possible, the political and moral connotations of other terms. Assistance in dying practices bear various names in different jurisdictions and according to the views of the person or group engaging in public debates. For example, in North America, “assisted suicide” is notoriously used by people who are opposed to assistance in dying, while proponents of this option prefer terms such as “physician-assisted dying” or “medical

assistance in dying” (Tucker & Steele, 2007). We use the term “assistance” to describe the provision, in response to a person’s request, of the conditions necessary to ending that person’s life by themselves or through the acts of another person. We consider the phrase “assisted dying” to be too passive, as it does not reflect the deliberate actions taken in the process of assisting a person’s death. We did not retain the term “medical” to qualify the assistance because assistance in dying is not considered a medical act in jurisdictions such as Switzerland (see Balard et al., 2021, in this issue; Gupta & Blouin, 2021, in this issue; Hamarat et al., 2021, in this issue). The term “dying” serves to stress that dying is a process, albeit shortened, in our context, by the assistance. Even for people who are not on a dying trajectory at the moment of the request for assistance, they engage in a dying process once the assistance has begun. Finally, we deliberately refrain from using the word “dignity” that is, for instance, employed in the phrase “death with dignity,” because we consider this terminology too morally loaded and polysemic (Gandsman & Burnier, 2014).

We also use the terms “provider-administered,” to designate situations in which another person directly administers what will cause the death of the person requesting the assistance, and “self-administered,” for situations in which the person who has requested assistance in dying performs the final act. However, we acknowledge that those two alternatives are not a strict dichotomy and that they exist on a continuum. Our editorial choice does not constrain the authors of the articles in this issue.

A Look at some comparisons

Comparisons of assistance in dying have mostly been conducted in quantitative public policy research and primarily aim to inform public policy on, for example, the feasibility of international comparisons of end-of-life policies (Boivin et al., 2015); existing data and the potential for abuse (Emanuel et al., 2016); the implementation of specialized health services for professional consultation in euthanasia in the Netherlands and Belgium (van Wesemael et al., 2009); numbers, characteristics, and trends over time (Steck et al., 2013); the impacts on “vulnerable” groups (Battin et al., 2007); adherence to legal request criteria (Lewis & Black, 2013); and legal notification, control, and evaluation procedures (Smets et al., 2009).

Researchers from Belgium, the Netherlands, and Switzerland developed and conducted a mortality follow-back survey in the three countries using a method first developed in the Netherlands in 1990 (Dierickx et al., 2020). This population-level comparative study

identified commonalities and differences in assistance in dying practices in the three countries. The strength of this approach is that the same questions were used in all three countries, which allowed the researchers to examine assistance in dying in an identical manner across the three contexts. The findings of the study “suggest that in addition to the legal context, cultural factors as well as the manner in which legislation is implemented play a role in how EAS [euthanasia and assisted suicide] legislation translates into practice” (Dierickx et al., 2020, pp. 72). Among those factors, the authors point to the attitudes of physicians and patients, the place where the assistance is carried out (home, institutional settings), and the primary care culture (Dierickx et al., 2020, pp. 71).

Our assessment of the quantitative literature leads us to conclude that international comparisons have so far focused on standardization and systematization rather than contextualization and theoretical problematization.

The emerging comparative qualitative research in the social sciences and humanities offers an interesting, if underdeveloped, complement to the findings of comparative quantitative policy research. We identify two examples that offer promising perspectives through which to deepen the comparative analysis of assistance in dying regimes.

First, Penney Lewis’ (2007) book *Assisted Dying and Legal Change* looks at “the process of legalization and its effects.” Through her exploration of the legal environment in which assistance in dying has been considered or authorized, Lewis “evaluate[s] the relevance of a particular legal experience to other jurisdictions” (p. 1). The contextual engagement of the work and the selected object of study (the process of legal change), which is at the crossroads of the legal regime, the political context, and public discourses, allow for a rich comparison of assistance in dying as an embedded phenomenon.

Another example is Frances Norwood’s (2009) ethnographic research on euthanasia in the Netherlands. Norwood’s study is not a comparative work as she only conducted fieldwork in the Netherlands, but as an American anthropologist she provides useful insights for developing comparisons, and attempts to draw lines of comparison between the Dutch and US contexts. Before drawing such lines, she carefully studies what euthanasia policies and practices mean in the Dutch context and how they are embedded historically, culturally, and politically (p. 216). Her work examines what she calls “euthanasia talk,” drawing on Michel Foucault’s concept of discourse. The notion of “euthanasia talk” has the

advantage of situating the analysis at two levels: the level of actual practices, including the conversations that may or may not lead to a life-ending act; and the level of cultural discourses about euthanasia that condition what is considered a “good request.” However, comparisons relying on cultural assumptions run the risk of essentializing a context and making differences between cases irreducible.

To make comparable what is not *a priori* comparable, researchers have to rely on a range of strategies, such as the ones used in Lewis’ work and underlying Norwood’s gaze. These two examples show how international comparisons of assistance in dying can be driven by the definition of a common object of study, by the construction of an object of study that crosses multiple scales of analysis, and by being informed by theories that grasp the intersections between different levels of analysis.

Key conditions for the international comparison of assistance in dying

With this special issue, we aim to open avenues for further research by identifying key conditions for the international comparison of assistance in dying in the social sciences and humanities. Each article in the special issue provides insights on those conditions.

Gupta, Downie, Cavalli, and Blouin take a comparative look at the legal definitions and the status of assistance in dying in jurisdictions that authorize these practices. Contrasting the terms and definitions used to legally describe assistance in dying practices reveals the potential for linguistic and conceptual confusion in comparing contexts if terms, concepts, and objects of study are not well-defined.

The second article, by Blouin, Gerson, and Cavalli, explores how the transnational circulations of persons, terms, and themes between contexts influence the construction of the assistance in dying public problem in some jurisdictions. Comparisons sensitive to context should pay attention to transnational circulations, including to the role researchers themselves play in constituting the issue as a public problem.

In the third article, Voléry and Toupet adopt an opposite perspective in two ways. First, instead of looking at the issue from an international perspective, the authors focus on one context to explore how the French state tries to overcome the contradictions that all “Western” states encounter in developing policies for prolonging life, drawing on Foucault’s biopower and Agamben’s thanatopower concepts. Second, they study a jurisdiction that does *not* authorize assistance

in dying, which also serves to illuminate the specificities of jurisdictions that authorize assistance in dying. Comparisons between contexts in which assistance in dying is authorized versus prohibited should be conducted in order to understand how the legal possibility of assistance in dying is embedded in multiple layers of governmentality.

Balard, Pott, and Yampolsky take on this task in their article comparing the place of relatives in the suicidal process of the elderly in France, which legally prohibits assistance in dying, versus in Switzerland, which tolerates it. After reviewing different analytical perspectives on the link between suicide and families, the authors mobilize two sets of data on the discourses of relatives to show how the two contexts modulate interpretations of the act. The article also raises the question of how the research design influences these discourses.

The subsequent article proceeds from other aspects of Foucault's work to compare ethnographic descriptions of "aid in dying" cases from Belgium and Switzerland. Hamarat, Pillonel, Berthod, Castelli Dransart, and Lebeer approach assistance in dying not from the perspective of official regulation but from below, by looking at the norms that concretely shape practices. This theoretically informed comparison of self-administered death in Switzerland and provider-administered death in Belgium considers assistance in dying as an "apparatus," in Foucault's sense, that researchers should explore in order to understand the dialectic between subjectivities and social norms in assistance in dying.

From a bioethics perspective, Gupta and Blouin also bring the question of norms to the forefront through an exploration of the inherent ethical judgment that informs the practice of assistance in dying, even though it is not always recognized as such. A comparative look at practice guidance in several jurisdictions authorizing assistance in dying demonstrates that the assessment of suffering exemplifies and crystallizes the tensions between individual, professional, and public norms that meet around decisions regarding the moral rightness of assisting a person's death.

Each article uses one or more strategies to create the conditions that make assistance in dying comparable across jurisdictions. They interrogate terminology. They explore contrasting contexts. They bring together distinct practices. They use theories that help to situate assistance in dying in broader contexts. They ask questions that unite the different contexts in atypical ways. All of these strategies can create the conditions for international comparisons of assistance

in dying as long as they treat assistance in dying as embedded in broader contexts. Instead of treating assistance in dying as a discrete practice, it needs to be grasped as being part of a continuum of practices, at the intersection of different levels of analysis, and in comparison with other regimes.

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