



# Parliamentary debates on death with dignity in Argentina: the rights of terminal patients on the legislative agenda, 1996-2012

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## Abstract

This article examines the regulation on terminal patients' rights in Argentina at two points in time: the first attempts to regulate end-of-life rights (1996), and the "death with dignity" law passed by the National Congress (2011-2012). Comparative analysis allows us to observe variations among the individuals and situations included in the legislation, as well as in the conceptualization of autonomy and the interventions that is considered lawful refuse. The political context and the differential way that "death with dignity" entered the legislative agenda in each period determined the public's construction of the problem and thus the extent and result of the debates.

Keywords: death with dignity; medicalization; euthanasia; bioethics; Argentina.

This article reviews the regulation of terminal patients' rights in Argentina, examining the conditions under which the issue emerged in legislative arena, and the way that medical management of end-of-life care (an expression which covers medical practices related to processes of dying) was constructed as a topic for public discussion at different periods.

Debates and references to "death with dignity" and a "good death," which have been around for a long time (Ariès, 2000; Kellehear, 2007), gained new significance and relevance with the medicalization and technification of the end of life in the West, a process influenced by the professionalization of the medical field, as well as by cultural, demographic and epidemiological changes (Illich, 1978; Ariès, 2000; Walter, 1997; Seale, 2000). Technical innovations such as pulmonary ventilation, cardiopulmonary resuscitation techniques and artificial nutrition, which led in the 1950s and 1960s to the possibility of offering intensive therapy, substantially altered end-of-life management in medical settings (Lock, 2002; Kind, 2009). The ability to keep vital organs functioning by technical means, which resulted in liminal states between life and death (Kaufman, 2000), gave a new status to medical decision-making in end-of-life care, and opened debates about the potential of these technologies and the limits to their use.

Within the framework of the emergence of bioethics as a discipline (Rothman, 1991; Irrazábal, 2015) and critiques of the medicalization of death and dying, such as the hospice movement (Clark, Seymour, 1999; Castra, 2003; Menezes, 2004; Floriani, Schraam, 2010), end-of-life care soon came to be seen as a "public problem." Decisions about when to prolong the life of a patient by artificial means and the criteria for withholding or withdrawing life-support measures had not been scrutinized until the mid-1970s, but they began to be discussed by different actors when doctors' authority to make these decisions came into question as a result of some controversial cases (Rothman, 1991). The legal ruling that granted Karen Quinlan's parents' request to disconnect her from the respirator that was keeping her in a vegetative state brought the topic to public attention for the first time in 1976 (Rothman, 1991). Cases such as those of Nancy Cruzan (Dworkin, 1994) and Terri Schiavo in the USA, Vincent Humbert (Pereira, 2007) and Chantal Sébire (Menezes, 2011) in France, and Dianne Terry and Tony Nicklinson in the UK (Richards, 2014, 2015), to name but a few, continued to fan debates about the rights of terminal patients (McInerney, 2000).

While attempts to regulate such rights go back to the 1930s, when the first societies seeking to legalize euthanasia were founded in the UK and the USA (Emmanuel, 1994), it was not until the 1990s that the first advances were made in this area. The first law authorizing euthanasia was passed in that decade by the Northern Territory of Australia (McInerney, 2000) and there were various similar initiatives by various states in the USA (Hillyard, Dombrink, 2001). In 2000, the Dutch parliament legalized euthanasia and assisted suicide (Weyers, 2006). Other countries have since followed suit.

In Argentina, controversies about end-of-life care have gained visibility in the last few years due to a series of controversial cases that brought up the issue of how death and dying were handled in medical settings; this provoked a debate that led to deliberations in the legislature and then to enactment of the so-called "death with dignity" law by the National Congress (Congreso Nacional) in May, 2012 (Argentina, 9 mayo 2012a). This law guarantees the right of patients with terminal or irreversible illnesses (or the right of family members in

their name) to refuse medical therapies or procedures when they are disproportionate to the prospect of improvement or when they prolong suffering. While the visibility and impact of the debates were largely unheard-of in Argentina, discussion of these issues in different public arenas, particularly in the legislature, was preceded on the local level by the passing of provincial laws and the systematic introduction of bills to regulate end-of-life care in the National Congress from 1996 on.

The interest of state agencies in regulating practices hitherto considered as belonging to the medical field, such as end-of-life decision-making, shows that they were being recognized and defined as topics of public interest or public “problems,” in the sociological sense (Gusfield, 2014; Schneider, 1985; Hilgartner, Bosk, 1988; Best, 2002). From this perspective, a situation acquires the status of problem via a process of social definition in which different actors intervene, all struggling to impose an interpretation of the problematic condition, its causes and its consequences, as well as of the actions the state should carry out to amend them. This process is seen in the introduction of an issue onto the legislative agenda, an arena designed to supply answers for topics that are successfully constructed as being of public interest. It also allows us to examine the competing interpretations in the official definition of the problem (Rein, Schön, 1993).

The aim of this paper is to describe and analyze legislation on the medical management of end-of-life care in Argentina, focusing on two relevant points in time: the presentation and discussion in the National Congress in 1996 of the first bills seeking to regulate the rights of terminal patients, and the passing of the so-called “death with dignity” law in 2011 and 2012.

Firstly, we analyze how the topic entered the legislative agenda, examining the first attempts to legislate patient rights in the National Congress. Secondly, we describe the construction of the end of life as a public problem in recent years, a process which led to deliberations and debate in the legislature and the enactment of a national law. Lastly, we provide a comparative analysis of both periods, showing the continuities and changes in the way of conceptualizing the issue.

## **Methodology**

This paper is part of a larger study of the discourses and debates about end-of-life care in Argentina in recent decades, in different public arenas. The research follows a qualitative methodological strategy based on collecting and analyzing documentary sources, such as legal rulings, newspaper reports and parliamentary bills, among others.

The sources on which the article is based include bills introduced in the Argentine National Congress, legislative procedures, laws passed and typescripts of parliamentary debates on the issue. Newspaper articles were also analyzed.

The bills and laws on death with dignity were found using search engines on the websites of both houses of parliament, using keywords such as euthanasia, death with dignity, palliative care, etc. More than forty bills were collected. We also analyzed the transcripts of parliamentary debates on the topic: one debate that took place in 1996 in the House of Representatives (Cámara de Diputados), and the debates that occurred prior to voting on the “death with dignity” law, from 2011-2012. These documents were analyzed on the

basis of aspects relevant to the subject: the issues and practices being legislated, the subjects (and conditions) affected and the rationales on which the bills and debates were based (the arguments and languages used).

We also searched the digital portals of the newspapers with the largest circulation in the country (*La Nación*, *Clarín* and *Página/12*), using keywords. The criterion for inclusion of articles was that they dealt directly with some aspect of the issue (cases in Argentina or abroad, op-ed pieces, coverage of legislative debates etc.). The articles were loaded into a matrix that allowed us to do a preliminary systematization of the data, and we performed a thematic analysis of the texts.

Material from the different sources was triangulated to characterize the context and characteristics of legislative initiatives throughout the period. The text of bills introduced by legislators, commissions' recommendations and session transcripts allowed us to characterize the alternations in legislative discussion on the topic at each stage analyzed: the features of the bills, the arguments used, and the points of agreement or disagreement. Journalistic coverage allowed us to supplement that information with data relevant for reconstructing the debates, such as legislators' remarks to other audiences, and stakeholders who actively took part in public discussions (bioethicists, patients and their relatives, and representatives of the Catholic Church, among others); we also analyzed the political negotiations that facilitated or hindered agreements, and the way the topic entered the agenda for the general public and the legislature in particular. We sought to trace similarities and differences between different features of the debates, bearing in the mind the contexts in which they occurred, the situations they sought to legislate, their references to patient autonomy, the voices authorized to speak and the nature of the arguments deployed, among other aspects.

## **Parliamentary deliberations on “death with dignity” in Argentina**

When were the first debates on the need to regulate end-of-life medical care and the rights of terminal patients in Argentina? How did this issue get put on the legislative agenda? What features did bills on the subject contain, and how did they vary over time? In the following section we analyze the legislation produced in this field, focusing on the situations envisaged in the legislation (and those excluded), the arguments behind the bills and the way the issue became a topic of public discussion in the two periods analyzed. In order to do this, we describe the moments of most intense parliamentary activity on the issue, which allow us to show the evolution of the debate over recent decades.

These debates occurred in different political and economic contexts that undoubtedly influenced the changes in the way the legislature approached the subject – although not, as we shall see, in a straightforward way. The first parliamentary debate on initiatives of this type took place in 1996, during Carlos Menem's second term in office (a member of the Justicialist Party, he was president from 1989-1999). Menem followed the recommendations of international lending agencies grouped into what became known as the Washington Consensus, and undertook a set of neoliberal economic and social reforms characterized by structural adjustment, the privatization of state enterprises and economic liberalization (Basualdo, 2010). In line with these fiscal adjustment policies, which were bolstered by a

discourse advocating the withdrawal or reduction of state intervention in different areas, the healthcare system was reformed and decentralized by the Menem administration. Along with other public-sector policies (such as the deregulation of social services) and the downturn in employment (due to the rise of unemployment and partial employment), the healthcare reforms negatively impacted medical coverage and care for the population (Belmartino, 2005; Messina, 2012).

The so-called “death with dignity” law adopted during the presidency of Cristina Fernández de Kirchner (2007-2015) emerged in the opposite political context, both in terms of economic and social policy trends and the role of the state in protecting and extending rights (Danani, Hintze, 2010). Discussion around a law for terminal patients in recent years can thus be inscribed within a set of progressive public policies aimed at broadening the threshold for citizenship and social inclusion, and specifically within a legislative agenda that has revived demands by different actors and given a green light for regulations defending the value of personal autonomy in decisions about one’s own body, especially in terms of sexual and reproductive rights (Jones, Hiller, 2015).<sup>1</sup>

### **The first bills and discussion in the legislature**

As we have seen, the first bills seeking to regulate the rights of the terminally ill in Argentina date back to 1996. Until that point, refusal of treatment was permitted by law 17.132 on the practice of medicine (Argentina, 30 ago. 1967), which was passed in 1967; one article in that law stated that health professionals must respect patients’ wishes if they refuse treatment. In the case of mutilating operations, the provider must have the patient’s written consent. In 1996, three bills were introduced by legislators from different parties, inspired by a case that became notorious after it was published in a tabloid with a large circulation in Argentina.

The case involved a diabetic patient who refused to have one of his legs amputated when it was affected by the advance of the disease. Since the patient’s refusal put his life in danger, the hospital where he was an inpatient requested legal authorization to go ahead with the operation regardless patient refusal. Based on prevailing legislation, the judge rejected the hospital’s request and backed the patient’s decision, recognizing a person’s right to “die with dignity” (Argentina, 18 sept. 1995).<sup>2</sup> The patient died days after the ruling. The article was published months after the ruling, on the front page of a newspaper (Un juez..., 9 feb. 1996), and although it did not lead to great debates (it was not taken up by other media and the topic did not appear again in the following days), it was enough to generate legislative initiatives, and one of the draft bills even cited the case in its preamble (Argentina, 1996a).

These early bills, introduced by both majority and opposition legislators,<sup>3</sup> sought to regulate the rights of terminal patients, in particular the right to refuse life-extending treatment, and they were aimed at adult patients in full possession of their mental faculties. One of the bills required only the patient’s statement and the consent of treating professionals to guarantee that right (Argentina, 1996b), whereas the others called for different procedures, such as an informed consent form signed by the patient, doctors and witnesses, and other requirements such as an evaluation of the case by an external medical board, a psychiatric examination, an ethics committee ruling and even a court order. All the bills included a provision forbidding

euthanasia, and declare in their preambles that they sought to avoid therapeutic cruelty, following the official position of the Catholic Church on the matter, recently seen in the encyclical *Evangelium Vitae* (Alonso, 2014).

Discussion of the bills continued in meetings of various parliamentary commissions, which made progress toward a common draft bill. The media also followed the progress of the legislative deliberations and kept the topic on the public agenda. One feature of the debates around these initiatives was the absence of those most concerned: neither patients nor relatives were present either in the first phase of parliamentary deliberation or at the various stages along the way. The experts called in by legislators and the media were generally representatives of medical associations, doctors with some training in bioethics, forensic medicine experts, representatives of the Catholic Church, or judges. Frequently, the speakers were professionals or representatives of institutions treating people with HIV/Aids, at the time a terminal illness that was very much in the public awareness.

The draft bill drew approval from different actors, although some voices, especially doctors, criticized the fact that it was limited to patients who were mentally competent adults, thus leaving out “the most extreme cases, ‘deep comas or vegetative states’ in which the patient has lost consciousness” (Muerte digna..., 23 mayo 1996; original emphasis).

The initiative was voted on the floor of the house, although at the legislative stage not a single bill mustered a consensus. Despite the points in common, when the respective commissions met, partisan logic prevailed: legislators from the governing party managed to issue a majority recommendation, while opposition legislators from the Radical Civic Union (Unión Cívica Radical) signed off on their own version of the bill. The two recommendations coincided on the central points (the right of terminal patients to refuse treatment), but they differed on procedural issues and on the situation of minors and those not legally competent (Argentina, 23 oct. 1996). The majority recommendation was that a judge should intervene in those cases and designate a legal representative, who could refuse treatment in the patient’s name. The minority bill, supported by the opposition, excluded minors and mandated that a judge should decide in cases where a legal representative was opposed to treatment. For mentally competent adults, both bills maintained the limitations on autonomous decisions present in the earliest bills: besides certification by the treating physician and an external medical board, they required a psychiatric evaluation to confirm the patient’s competence and freedom to make decisions (stating that the patient was not depressed or under pressure to make the decision).

This restricted, tutelary concept of autonomy seen in the two draft bills was matched by the low visibility of the notion of “patients’ rights” throughout the whole discussion process; the notion was treated almost as a threat to medical authority. An opinion piece by a well-known bioethicist mentions the suspicion with which legislators and medical professionals referred to patient autonomy over decisions about their health and their bodies.

Certain physicians are suspicious because they fear falling into “euthanasic” practices and are looking for definitions that will allay their doubts; ‘there are others who fear that this law could allow patients to interfere in certain medical decisions, and they believe this could lead to a dangerous use of such authority.’ ... This bill should explicitly require a certain respect for patients’ rights. ‘Speaking of people’s rights or preferences

does not imply sitting on the other side and stirring up conflict between doctors and patients' (Luna, 5 ago. 1996; double quotation marks show original emphasis; single quotations marks, our emphasis).

None of the bills explicitly stated which medical practices and treatments were subject to refusal by patients. However, in the parliamentary debate and in statements to the press, the authors of the bills declared that this right did not extent to life-support measures such as a mechanical ventilator or artificial hydration or nutrition. Stopping or withdrawing such types of treatment was associated with euthanasia, a practice specifically prohibited in the wording of both rulings. A newspaper commentator remarked that:

It suddenly became clear that it won't include actions that imply 'euthanasia, such as, for example, giving terminal patients a lethal injection or disconnecting life-support machines.' ... But the law does not allow one to ask to be disconnected from a ventilator or to give a lethal injection, since that crosses over into euthanasia (Zapiola, 24 jun. 1996; our emphasis).

During the parliamentary meeting when the two recommendations were discussed, various legislators, mainly members of the opposition, pointed out some important drawbacks. The bills' failure was largely caused by legislators from the progressive parties (contrary to what one might assume), who were then joined by legislators from the party that signed the minority ruling.<sup>4</sup> The main objections to the initiative were that it was unnecessary, since the right to refuse treatment was already specified in current legislation (in the law on practicing medicine), and that such a bill might lead to euthanasia, especially in more vulnerable populations. These objections stem from the sociopolitical context in which the vote on the law took place, and specifically the set of neoliberal reforms of the health sector implemented by the party in government, which had led to a deterioration in the state of healthcare (Belmartino, 2005).

While the expressed motive of those leading the death with dignity initiatives was to avoid therapeutic cruelty, the tone that predominated in the debates was not so much concern about the dehumanizing effect of technology, but rather the vulnerability of dying patients in the healthcare system, largely driven by the visibility of death due to HIV/Aids. In this framework, the obstacles and precautions included in the legislation with regard to the exercise of autonomy, as well as the refusal to pass the law, were intended to protect terminal patients; there was a fear of abusive practices by family members and by health care institutions, who might attempt to reduce costs by forcibly interrupting treatment, violating basic rights. Several years later, recalling the voting process on those bills in an interview, Elisa Carrió, a congresswoman from the Radical Civic Union and a signatory to the minority ruling, stated that:

When we were due to pass the law – and I had signed off on the bill – I was going down to the congressional meeting room and a health minister from one of the provinces came up to me and said, "It's lucky they're going to sign this, Lilita, because it will allow us to save a lot of money on cancer medications." And right then I realized that it could mean a quick death for needy elderly people. So I went into the meeting and suspended the proceedings (La política..., 23 oct. 2007).

Ultimately there was no vote on the bill and it was returned to the Health Commission and not debated on the house floor again. In subsequent years, bills on the rights of terminal patients were repeatedly introduced in both chambers of Congress, by legislators from different parties and political persuasions. The themes (and languages) seen in these bills partly reflect the debates fueled by highly-publicized cases abroad, like that of Terri Schiavo in the USA.<sup>5</sup> Besides the increasing number of issues that were becoming objects of legislation (living wills, palliative care), there was a growing tendency to adopt the language of “human rights” and affirm the value of patient autonomy, which were only hinted at in the early debates. None of these draft bills reached the voting stage or had any impact until the issue became a matter of public debate once more, thanks to media coverage of some cases in 2011. Publicity about the cases of Melina González and Camila Sánchez stirred up debate on end-of-life care and patient rights, giving the issue unprecedented visibility in the country.

### **Passing the “death with dignity” law**

In March 2011, 19-year-old Melina González died of a degenerative illness in a public hospital in the city of Buenos Aires. Melina had requested palliative sedation to relieve the pain caused by the advance of her disease. Her request was denied by the doctors treating her, who believed it could not be granted without a court order. The case appeared in a national newspaper in February; Melina asked for relief of her suffering at the end of her life and called for Argentina’s president and legislators to pass a “death with dignity” law covering cases like hers. Her request struck a chord with some legislators, who became aware of the issue and presented the first draft bills,<sup>6</sup> but the issue did not really take off in the media and the legislative arena until some months later, when the case of Camila Sánchez hit the news.

At that point, Camila was a two-year-old girl in a permanent vegetative state due to oxygen deprivation while she was being resuscitated following cardiorespiratory arrest at the moment of birth. After a year with no change in her health status, and backed by rulings from various ethics committees, her parents asked the doctors to take her off the ventilator keeping her alive. The doctors refused to discontinue treatment without a court order endorsing the decision. The parents then decided to turn to legislators and the media to call for a law to cover their request – as in the case of Melina: “In this country we need a death with dignity law that will cover all the people going through terrible situations like this one. A court order begins and ends with Camila. By this point, I’m convinced my daughter came into this world for a reason, and maybe this is why, to get this law passed,” Selva said (Iglesias, 24 ago. 2011).

The broad media coverage of this case led to attempts to legislate the issue. In addition to the initiatives discussed earlier, that same year there were ten more draft bills, signed by congressmen and senators from different parties: some proposing wording for a new law and others proposing modifications to law 26.529 on patient rights, passed some years earlier, which included isolated articles on “death with dignity.” There were also public hearings with experts (including medical professionals, lawyers, and bioethicists), to which patients’ relatives were also invited. The first instances of consensus occurred in the House of Representatives (Cámara de Diputados) and a majority recommendation was issued (Argentina, 25 nov. 2011), backed by legislators of different political affiliations.<sup>7</sup> The agreed-upon draft bill, which was



later signed into law, guaranteed the right of patients with terminal or irreversible illnesses (or of relatives in their name) to refuse therapies or medical procedures that were disproportionate to the prospect of recovery or that prolonged the dying process. It also regulated advance directives or living wills, documents that allow people to communicate their preferences about the type of care they do and do not wish to receive in the future. The minority opinion, signed only by one congressman aligned with the Catholic Church, recognized the same rights but ruled out the possibility of allowing patients to decline artificial hydration and nutrition, which had been explicitly listed among the practices that could be refused.<sup>8</sup>

One of the distinctive elements of the law that was eventually passed is its full recognition of patient autonomy (Argentina, 9 mayo 2012a). Unlike earlier draft bills, it granted no role to medical practitioners, “psy” professionals or any other actor in evaluating the validity of patients’ decisions. The idea that fighting for patients’ rights might detract in any way from doctors’ authority did not come up in discussions. An excerpt from statements by one of the senators exemplifies this shift in the consideration of autonomy and the acknowledgement of patients as subjects with full rights:

But I think it is very important to state that in no way do we have to relinquish any of the victories we have achieved in recent years, when people’s autonomy has become extremely important. ‘I don’t think a bioethics committee or a psychologist should make decisions for me or for my family about something as central as my own death’ (Speech by Senator Corregido, of the Justicialist Front party, Argentina, 9 mayo 2012b; our emphasis).

The central role of the principle of autonomy in these debates is also seen in the protections granted to minors and those declared legally incompetent, possible beneficiaries of the law, whose right to be consulted and to participate in decisions regarding their own health is recognized.<sup>9</sup> In such cases, the next of kin may grant their consent to refuse or cease treatment.

Beyond advancing the recognition of autonomy, the modifications to the law did not change the statute on euthanasia and assisted suicide, practices that are still penalized under Argentine law. Euthanasia (understood as a direct action intended to cause death) functioned as the moral limit in the debates and was often used by legislators as a safeguard allowing them to make headway on polemic issues, such as listing treatments considered basic care by the Catholic Church. In that regard, the law states that all “therapies or medical or biological procedures” may legitimately be refused, including life-support measures: both more complex treatments like mechanical ventilators and less complex measures, such as artificial feeding and hydration.

The inclusion of these practices, and the general tone of the debates, in which there are constant references to the need to limit the use of technology to allow death to occur, reveal how “death with dignity” was constructed as a problem in those years. Clearly influenced by the Camila Sánchez case, the types of case being legislated and envisaged by the legislators involved disorders of consciousness: vegetative states and profound comas. The intensive – and unjustified – use of technology to prolong the dying process functioned as a sort of framework for the debates. References to “therapeutic cruelty” and the dehumanizing effect of the use of technology in end-of-life care left out issues such as the quality of care that the healthcare system offers patients with terminal illnesses. Such issues were brought up by

minority voices, who took advantage of the moment to call for a law that would create and finance a national palliative care program.

One final point worth stressing in the debates and the process of passing the law is the level of consensus seen on the initiative from the outset. The law was voted in by a wide, pluralistic majority in the House of Representatives (142 votes in favor and only six against)<sup>10</sup> and in the Senate (56 votes in favor, none against). The consensus was largely due to legislators' perception of the need for and importance of such a law. The wide coverage of the cases commented on earlier, and the active presence of patients' relatives, who took part in every stage of the process, gave visibility to the law's potential beneficiaries. Legislating on the matter was read at that time as a gauge of Congress' willingness to provide concrete answers for painful, urgent situations, seen as "debts to society," in a political context of broadening of rights and a clearly progressive legislative agenda. This is seen in a speech by one of the congressmen at the moment the law was put to the vote; the tone resembles that of various colleagues in both houses:

I feel very happy and proud to belong to an institution that is dealing with these issues, ones we are advancing on like autonomy, liberty and dignity; and we're doing it not just on these issues, which are very important, but also, I hope, for many more still pending responses from us (Speech by Senator Martínez, of the Radical Civic Union, Argentina, 30 nov. 2011).

## **Overview of the death with dignity debates**

What points of continuity and change are seen in the legislative debates on end-of-life care in recent decades? What led to these debates and what implications do they have? To what extent do they reflect varying perceptions of end-of-life rights? In the discussion about end-of-life patient rights, disputes centered on the question of who is qualified to make decisions, in what situations and via what procedures. In this section, we discuss the principal variations on these issues during the period (see Table 1), approaching the debates from a comparative viewpoint.

The first point of departure involves the subjects affected by the initiatives at the two periods analyzed. While in recent years there has been broad consensus about the need for the legislation to include not only people who were legally competent, in the early debates there was resistance to including minors and the incompetent in the statute. In both periods, the interventions and treatments that patients could and could not refuse varied, distinctions that separate legitimate decisions from those considered to be euthanasic. While in the first debates interruption of life-support measures was considered a euthanasic practice – an author of one of the draft bills told the media that "death with dignity does not imply disconnecting anything," (Ahora..., 10 jun. 1996) – the law that was passed in 2012 explicitly provided for withholding and/or withdrawal of these treatments, without provoking major controversies. In both debates, however, euthanasia was seen as the moral limit of the practices accepted in the legislation, although the concept of what constitutes euthanasia has been modified in part, showing that the limits of what is seen as morally acceptable or tolerable could shift somewhat.

**Table 1: Parliamentary debates on terminal patients' rights, 1996-2012**

	First debates (1996)	Death with dignity law (2012)
Subjects involved	Consensus on competent adults; disagreement on minors and the incompetent	Adults and minors; competent and incompetent
Practices covered	Abstention from new treatments (no withdrawal of life support)	Refusal or withdrawal of all kinds of treatments (life support)
Main condition	Chronic and/or degenerative diseases	Vegetative states
Patients and relatives	Absent from debates	Key to emergence of debates
Concept of autonomy	Tutulary autonomy. Subject to expert evaluation	Full autonomy
Political context	Neoliberal reforms of the health sector	Discourse of broadening rights
Political logic	Low visibility of beneficiaries. Cost to legislating on sensitive topics	High visibility of beneficiaries. Benefit to legislating on sensitive topics

Source: Created by the authors.

Another difference between the discussions lies in the understanding of the notion of autonomy and patients' rights, which evolved from a restricted and tutelary notion of autonomy, in which patients' decisions had to be endorsed by healthcare professionals, who were granted the last word, to a scenario in which autonomy (exercised to the full, with no mediators) is upheld as a central value. The triumph of autonomy for decisions about the body is part of the gradual cultural adoption of the values advocated by bioethics, but it remains a limited triumph in this field, however, given the exclusion of topics like euthanasia and assisted suicide. Public discussion of the end of life was only possible in both periods because those two issues remained off the agenda.

The influence of the Catholic Church (and the legislators' religious beliefs) in parliamentary definitions surely played a role in excluding more radical positions.<sup>11</sup> However, religious actors did not play a central role in the debates. In fact, the presence and intensity of these actors' demands was significantly less than in parliamentary deliberations on other sensitive topics for the Church, such as egalitarian marriage or sex education (Felliti, 2011; Esquivel, Alonso, 2015). The position of the Church in Argentina – or its representatives – was similar in both periods: cautious support for the bills, as long as they aimed to reduce cruel treatment in the last stages of life and continued to prohibit euthanasia, values shared by Catholic doctrine on the subject (Alonso, 2014). The Church's warnings were mostly concerned with the risk of a "slippery slope," expressed as a fear that the supposed respect of personal integrity might be used to violate the rights of the most vulnerable citizens, or that the initiatives would mean a move towards legalizing euthanasia. In recent debates, the Church also opposed any explicit authorization to withhold practices such as artificial hydration or nutrition, considering these to be passive forms of euthanasia; this demand was not heeded by the legislators (Alonso, 2014).

Meanwhile, concepts of autonomy and the conditions and procedures for exercising it must also be framed within the broader context surrounding the debates. In recent years, bills defending the rights of terminal patients have been inscribed within a progressive

legislative and political agenda that seeks to broaden rights and affirm individuals' freedom to make decisions about the body, as seen in the laws on egalitarian marriage and gender identity, among others. However, within the framework of the rise of neoliberal policies that severely impacted the health sector in Argentina, the first initiatives on end-of-life care were interpreted by some legislators not as recognizing rights but as rendering vulnerable sectors more defenseless: in their view, supporting those bills meant endorsing non-intervention by the state in healthcare and the preservation of life. Both contexts, however, influenced legislators' perception of terminal patients: from potential victims of doctors' and health institutions' power, they came to be perceived as subjects with full rights.

One of the most notable differences between the two periods was the way the topic emerged onto the public agenda, which strongly influenced the way it was defined and is undoubtedly the factor that most accounts for the changes described. In recent years, demand for a law came initially from individual patients and relatives, but over time they came together as an advocacy group actively involved in keeping the issue on the agenda. At the outset and in subsequent parliamentary deliberations on the issue, patients' relatives became authorized voices in the discussions, both in the media and in Congress. Strategic coverage of their demands in different public arenas helped to bring them visibility and to obtain recognition from society (and the legislators) for them. In the first debates, these actors were absent. The first bills, while inspired by particular cases, were introduced by legislators who were interested in the topic; those affected did not play a leading role.

The cases that sparked the debates also affected the type of patient or situation envisaged by the legislators. In 1996, the bills were mostly aimed at adult patients with a terminal or incurable illness, in full possession of their faculties, who decided to refuse a new treatment. They were patients in the last stages of a chronic or degenerative disease, such as cancer or HIV/Aids, illnesses which at that time were seen as synonymous with death (Sontag, 2003). The cases that shaped the image of terminal patients in more recent debates were different: the figure involved was a person in a vegetative state, deprived of the ability to make decisions, and suffering a prolongation of death due the intervention of technology.

The progressive legislators' refusal to back the bill in 1996, which led to its failure to pass, and the broad consensus about passing the law in 2012 (it was supported across the political spectrum), shows that the fate of these initiatives was influenced more by context and by public definition of the problem than by the legislators' ideological bent or personal convictions. In 1996, partisan logic dominated the discussions, and disputes between the majority and the opposition parties prevented passage of the law despite the significant similarities in the recommendations issued by either side; in 2011, however, consensus between the different forces and parties gave legislators the freedom to vote according to their convictions. As in the voting on other laws in recent years (assisted reproduction, gender identity), the 2011 initiative succeeded because of these agreements and was voted in almost unanimously in both houses, independently of party affiliations.

A bill with the potential to divide the political blocs (due to its sensitive nature) or one that yields little benefit in political terms (due to the small number or lack of visibility of the beneficiaries), or involves a high cost (due to its low popularity or small number of votes in favor) has less chance of getting to the voting stage (Rein, Schön, 1993; Calvo, 2007): issues

like abortion or matters related to euthanasia can be perceived in those terms by legislators. Public discussion of end-of-life care was not feasible either in social or political terms in 1996. Because of the low visibility of the beneficiaries and the likely associations with euthanasia, legislators saw a bill on the matter as involving more costs than benefits. In 2011 and 2012, on the other hand, the presence of patients and families and the level of visibility of the dramas they represented changed the equation: discussing “death with dignity” came to be seen by legislators as a matter of social and also political interest. Within this framework, both legislators and the institution of the legislature stood to gain from taking a stand on sensitive issues.

### **Final considerations**

In this article, we have analyzed Argentinian legislation on patients’ rights at the end of life, comparing the periods when the topic was most intensely debated in the national Congress: the first parliamentary discussion in 1996, and the more recent deliberations leading to enactment of the so-called “death with dignity law” in 2012. Based on a range of documents, we have described the details of both processes and examined the variations in terms of the people and situations included in the legislation, the conceptualization of autonomy, and the interventions that were seen as legitimately rejected in each period. We also analyzed the ways in which the topic entered the public arena (and particularly the legislative arena) and the context and political logic that framed the responses and positions of the legislators, comparing the variations over time.

Decisions about end-of-life care involve ideas about personal dignity and individual liberty. The changes that took place in the debates and legislative initiatives show how the values of personal autonomy and patients’ interests came to play a central role. Also, the conditions under which the topic entered and overtook legislative agendas helps define the frameworks in which end-of-life care is constructed as a problem. As seen in the sociology of public problems, the way a given issue is defined and constructed affects the lines of action that emerge in response (Gusfield, 2014). The differential way that “death with dignity” entered the public sphere and the terms in which it was defined in each period largely determined the practices and situations discussed in the legislature, as well as the extent and result of the debates at both periods.

The discussions that took place in the legislative arena cannot, however, be isolated from the broader social context in which they are inscribed, as shown by the interconnection between the different arenas in which the issue came to be seen as a matter of public interest, as well as the visibility of cases in the media. In this sense, parliament functions as a sounding board that picks up meanings and discourses that socially define the nature of what is seen as a “death with dignity.”

As seen in the debates analyzed and the variations observed, the end of life and notions of “death with dignity” must be understood not merely as biological, static concepts, but as an open space for moral, scientific, religious and of course political discourses, which shape the socially acceptable ways of dying.

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## NOTES

<sup>1</sup> The laws of comprehensive sex education (2006), egalitarian marriage (2010), gender identity (2012) and assisted reproduction (2013), among others.

<sup>2</sup> For an analysis of the emergence of this notion in Argentine jurisprudence, see Alonso (2016).

<sup>3</sup> The people who signed the three bills were José Corchuelo Blasco and Carlos Álvarez, legislators from the majority Justicialist Party (PJ); Miguel Bonino, from the Radical Civic Union (UCR), the leading opposition party at the time; and Luis Polo, representing Modin, a right-wing party.

<sup>4</sup> Legislators like Juan Pablo Cañero, of Frepaso, voiced the main objections and sought to have the recommendations discussed again by the Health Commission, a request which was later seconded by UCR legislators and a few from the Justicialist Party (PJ).

<sup>5</sup> From 1997-2000, nine draft bills were presented that sought to correct the drawbacks to the bills debated in 1996 – such as regulating decision-making in the case of minors and the mentally incompetent. From 2001-2003, ten bills were introduced that included regulation of “living wills,” a legal tool to guarantee that one’s decisions about treatment will be respected in case one is not able to communicate them in the future. In 2005, the issue was given a new boost by the coverage and impact of the Terri Schiavo case in the USA, and there were a further five bills introduced, four of which sought to regulate “living wills” or “advance directives.” From 2006-2010, there were another ten bills.

<sup>6</sup> Congressman Miguel Bonasso, of the Diálogo por Buenos Aires party, and senator Samuel Cabanchik, of Project Buenos Aires Federal, presented bills to regulate the right of terminal patients to refuse treatments in light of this case.

<sup>7</sup> Unlike the earlier period, in which party loyalty prevailed, the majority recommendation was supported by legislators across the ideological spectrum, of varying political positions (from the governing Justicialist Party and its allies to representatives of the opposition). The ruling was signed by congressmen for the Victory Front (Frente para la Victoria), the Justicialist Party, the PRO, the UCR, the Civic Coalition (Coalición Cívica) and the South Project (Proyecto Sur), among others. During the voting in both Congress and the Senate, the consensus among political forces held.

<sup>8</sup> The minority ruling, which echoed the position of the Catholic Church on this issue, was signed by congressman Julián Obiglio, of the PRO, who later voted in favor of the majority ruling. The statute and the legitimacy of suspending artificial hydration and nutrition, considered basic care by the Catholic Church, was the only crux of discussion during the legislative stage. For more in-depth discussion of the position of the Catholic church in Argentina regarding the death with dignity debate, see Alonso (2014).

<sup>9</sup> One of the law’s provisions states that: “Children and adolescents have the right to intervene as stipulated in law 26.061 in decision-making about therapies or medical or biological procedures involving their life or health” (Argentina, 9 mayo 2012a).

<sup>10</sup> Six congressmen from different parties, mostly from the interior, voted against it: legislators from the Justicialist Party from San Luis and San Juan, two congressmen from the province of Catamarca, belonging to a center-left coalition, a member of Christian Democracy (Democracia Cristiana) from Mendoza and one congresswoman from the city of Buenos Aires, linked to the evangelical church. None gave reasons for the vote in the session, nor did they make public statements against it.

<sup>11</sup> Esquivel (2015) discusses the influence of religious institutions and beliefs in the creation and wording of draft bills on issues of sexuality and reproduction in the National Congress, noting the tensions between the advance of secular values and the persistence of church-based sources of legitimacy. In Brazil, Gomes, Natividade y Menezes (2009) have analyzed the influence of religious values on the handling of bills on issues relating to sexual rights and autonomy over one’s own body (like euthanasia).

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