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The rights of the dying: the refusal of medical treatments in Argentine courts

Derechos en el final de la vida: el rechazo de tratamientos médicos en los tribunales argentinos

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ABSTRACT This paper addresses the judicialization of end of life medical decision-making, as part of the advance of the justice system in the regulation of medical practice and the rise of recognition of patient autonomy. The article analyzes, from a sociological standpoint, legal decisions regarding treatment refusal at the end of life produced by the Argentine courts between 1975 and 2015. Based on a qualitative design, 38 sentences collected from jurisprudential databases using key terms were analyzed. First, judicialized cases during the period are described; these are characterized by a high proportion of claims presented by health institutions, a pro-treatment bias in the legal actions requested, and a high percentage of unnecessary litigation in the absence of conflicts or in situations that do not require court intervention. Second, legal and extralegal factors affecting the justiciability of decisions to refuse or withdraw medical treatments, such as changes in the law and processes of politicization of claims, are analyzed.

KEY WORDS Treatment Refusal; Right to Die; Right to Health; Bioethics; Argentina.

RESUMEN El artículo aborda la judicialización de decisiones médicas en el final de la vida, en el marco del avance de la justicia en la regulación de la práctica médica y de un mayor reconocimiento de la autonomía de los pacientes. El artículo examina, desde una perspectiva sociológica, la jurisprudencia producida por tribunales argentinos entre los años 1975 y 2015 en torno al rechazo de tratamientos médicos en el final de la vida. Siguiendo un diseño metodológico cualitativo, se analizan 38 fallos, relevados a partir de descriptores en bases de datos jurisprudenciales. En primer lugar, se describen los casos judicializados, caracterizados por el protagonismo de las instituciones de salud como litigantes, el sesgo pro-tratamiento de los pedidos, y el alto porcentaje de demandas en ausencia de conflictos o en situaciones que no requerirían intervención judicial. En segundo lugar, se analizan los factores judiciales y extrajudiciales que inciden en la justiciabilidad del rechazo de tratamientos, como cambios normativos y procesos de politización de los reclamos.

PALABRAS CLAVES Negativa del Paciente al Tratamiento; Derecho a morir; Derecho a la Salud; Bioética; Argentina

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INTRODUCTION

In July 2015, a ruling issued by the Argentine Supreme Court of Justice authorized the withdrawal of life support from a patient who had been in vegetative state for more than 20 years.(1) The ruling confirmed the constitutionality of Act No. 26742, better known as "Death with Dignity" Act, which guarantees the rights of patients suffering from terminal or irreversible diseases (or the rights of the relatives acting on the patients' behalf) to refuse medical treatments or procedures when considered unreasonable in view of the impossibility of improvement or when these procedures prolong agony.(2)

In Argentina, this ruling stirred up debate on the rights of patients at the end of life, as well as the role of justice in these types of decisions.(3,4,5) In the last decades, first in the central countries and then in different parts of the world, medical decisions and their consequences, which had been kept in the privacy of the physician-patient relationship, started to be taken to judicial courts.(6,7) This article analyzes the controversies over refusal to medical treatment at the end of life handled by Argentine courts, in the context of wider processes of judicialization of social relations and changes in medical practice, which have been defined by a greater acknowledgement of patients' autonomy regarding decisions over their own health and body, as well as the involvement of new actors (such as judges and experts in bioethics) in the regulation of decision-making.

The onset of the judicialization of medical decision-making at the end of life stems from the advance of medicalization and technification of the management of death and dying.(8,9) During the second half of the 20th century, the advances in medical technology contributed to maintaining organ functioning and vital functions by artificial means, prolonging life and agony.(10,11) In this context, controversial cases involving physicians, whose authority on these types of decisions were being questioned, started to become publicly known.

In this respect, Quinlan case set a precedent, when raising in the public sphere for the first time the discussion on patients' rights to refuse life support. In 1976, the U.S. Supreme Court ordered the withdrawal of the medical ventilator that kept Karen Quinlan alive while she was in vegetative state. This decision legitimized the parents' request submitted in view of the physicians' refusal to suspend the medical intervention. This case became one of the first precedents of medical practices and decision-making at the end of life regulated by courts and judges.(7)

The aim of this article is to both describe and analyze the judicialization of the requests related to the refusal to medical treatment at the end of life in Argentina, and also to examine the factors that promote or hinder the process of taking these types of decisions to courts of justice.

In recent years, sociologists in Latin America have paid special attention to the judicialization processes regarding different issues. Such processes refer to the expansion of the judges and courts' jurisdiction and the individuals and groups' adoption of a discourse based on rights as a means to file complaints or claims.(12,13, 14, 15, 16, 17, 18,19)

In the field of health, the bibliography about judicialization is focused on the analysis of controversies over the right to health, fundamentally due to the increase of claims related to the access to or the expansion of the coverage of medications and medical services.(20,21,22,23,24,25,26,27) However, the judicialization of medical practices, such as medical malpractice lawsuits and disputes over decisions both at the beginning and the end of life,(28,29) has drawn less attention.

This article has been written within the framework of an ongoing research study that addresses medical management of the dying as a public issue in Argentina, and examines how this issue is approached in different spheres (legislative, legal and medical, among others). At this point, this article seeks to analyze the existence and the characteristics of the debates held in the legal field based on a number of rulings issued by the Argentine courts between the years 1975 and 2015.

This was the starting point to think about the aspects relevant to the sociology of health, such as the judicialization of the medical practices, patients' rights, the role of health actors and the discourses that regulate and condition the process of decision-making, and the physician-patient relationship.

In the context of this project, the process of politicization of the claims over the rights at the end of life has been analyzed. This process eventually led to the legislative analysis and the enactment of the so-called "Death with Dignity Act" in Argentina,(3) and the participation of Catholic actors in this process.(4) In a previous article, there was discussion about the context and social implications of the judicialization of the refusal to medical treatment from a socio-historical perspective. It analyzes the changes in the discourses and arguments presented in the controversies over medical decisions at the end of life.(30) This paper seeks to describe the litigation process related to the refusal to medical treatment at the end of life and, by way of discussion, to analyze the conditions required to judicialize these types of disputes.

METHODOLOGY

The research study that serves as a framework for this article adopts a predominantly qualitative methodological design, based on the collection and analysis of data from different sources. In order to write this article, rulings issued by either national, provincial or municipal Argentine courts between the years 1975 and 2015 have been examined. The period analyzed covers from the first cases of judicialization of this issue to the recent decision produced by the Argentine Supreme Court of Justice that endorses the constitutionality of Act No. 26742.(1)

The sentences were searched in five jurisprudential databases: one of the most important Argentine publications on legal matters, *La Ley online* (since 1975); and the online databases of the Supreme Court of Justice of the Argentine Republic (since 1994), the Supreme Court of the Province of Buenos Aires, the Supreme Court of the City of Buenos Aires and the *Infojus* news website. The search on each database was carried out using key words. In view of the changes in the judicialized cases, a variety of specific key terms were used, such as "dignified death," "euthanasia," "conscientious objection" and "bioethics," among others. The *corpus* of the research study was completed with rulings mentioned in previous sentences or articles published in journals which had not been found through key terms.

Rulings were included in the *corpus* after having read only the abstract of the sentence or the full text of the sentence where the information provided was insufficient or unreliable. As a criterion for inclusion, it was established that the rulings should address the refusal to medical treatment, either in end-stage cases or in the situations where the omission of or the refusal to medical treatment should risk patients' life. Rulings which did not meet this criterion were excluded.

The *corpus* finally comprised 38 sentences. The text of such sentences was encoded and analyzed applying qualitative techniques through the ATLAS.ti computer program, following the analysis scheme suggested by Gloppen(31): first, the particulars of the claim (plaintiff and subject matter) were analyzed; and, second, the characteristics of the ruling (the judge's decision and supporting arguments) were examined. For the descriptive analysis of the corpus, a matrix was elaborated including data related to the ruling, the complaint and the plaintiffs (plaintiff's particulars, medical condition or pathology in question, litigation strategy, and legal grounds for the complaint), and the judicial decision (final sentence and legal grounds), among others. Both approaches contributed to thorough understanding of this issue.

Collecting an exhaustive corpus of sentences on this issue in such a long time period is complex due to the browsers' time limitations and the selective inclusion of sentences in the databases. Despite these limitations, the set of documents under discussion help

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characterize the processes of judicialization of the refusal to medical treatment regardless of the paradigmatic sentences, which are mentioned in the studies that analyze the jurisprudence from a legal or bioethical perspective.(32,33,34,35)

RESULTS

Right to refuse medical treatments in Argentine Courts

Which are the features of the judicialization with respect to the refusal to medical treatments in Argentina? Which types of cases are heard in court and what are the reasons why plaintiffs resort to justice? Who files these complaints and what answer do courts provide?

The first aspect to be noted is the low level of judicialization of the refusal to medical treatments at the end of life. Regardless of possible omissions in the collection of data, due to either inconsistency in the databases or the particular characteristics of these cases,[a] the number of sentences issued by Argentine courts is very low. A total number of 38 sentences were found for the period under analysis and, although the number has increased since the 1990s, no significant fluctuations were observed during this period. In recent years, despite the fact that this issue has become more visible as a result of public debate and the enactment of Act no. 26742,(3) no notable increase or decrease in this type of cases was registered when compared with previous years. In comparison with the importance that the judicialization of health-related issues has acquired in the last decades, especially claims related to medical treatment coverage,(24,25,26) the limited number of sentences accounts for the low level of litigation over the right to refuse to medical treatment.

Who resorts to justice to settle disputes over medical decision-making at the end of life? The judicialized cases on which the court has ruled are mainly initiated by professional physicians or health institutions, such as public hospitals and private clinics and, to a lesser extent, by patient's relatives (parents, children and spouses). Only three sentences were issued upon patients' request at court, either to solve disputes about medical decision-making or to guarantee that their wishes will be respected.

Regardless of who the plaintiff is, in Argentina the reasons why these decisions are judicialized are associated with a pro-treatment bias. Most sentences are issued in response to requests for authorization to perform or continue medical procedures rejected by patients, even if they consist in either a blood transfusion or a surgery.

The majority of the cases presented by health professionals and institutions are complaints seeking the judicial authorization to perform medical treatments rejected by patients or their relatives. A good example of this type of cases may be seen in a ruling issued by Judge Pedro Hooft, which is frequently cited in jurisprudence. In this case the judge's decision was to dismiss the request for authorization submitted by a health institution to amputate a limb from a diabetic patient who refused to undergo such procedure.(36)

The requests submitted by the patient's relatives are classified into those requesting the discontinuity or non-performance of a medical treatment – in those cases where patients are incapable of exercising their will – and those opposing the patients' own decision to refuse medical treatment and claiming at court for the forced performance of such procedures. A good example of the former request, among others, is the case referred to in the last ruling on this matter issued by the Argentine Supreme Court of Justice, in which the sisters to a patient in vegetative state demanded the withdrawal of life support.(1) The latter type of demand is illustrated in the request for a forced amputation presented by one of the children to a patient who was undergoing a severe chronic disease and rejected such procedure.(37)

The few complaints filed by patients aim to guarantee that their decision to set limitations on medical procedures be respected, either to avoid any treatment against their will or to prevent health professionals or institutions from refusing to respect such decision. The first judgment of the Argentine Supreme Court of Justice over the refusal to medical treatments – the Bahamondez case – is initiated through a complaint filed by a patient, in which the patient required professionals to respect his refusal to receive a blood transfusion based on religious grounds.(38)

The jurisprudence consulted does not include cases in which relatives or patients resorted to justice to demand the performance of medical treatment once professionals had already decided on the discontinuity or non-performance of procedures.

Regarding the reasons for the judicialization of medical decisions at the end of life, most of them are due to disputes related to the refusal of blood transfusions by Jehovah's Witnesses, a religious group that has set significant legal precedents on this issue in many countries. These types of cases were the first to be filed with court and led to the issuance of several judgments by the Argentine Supreme Court of Justice, as illustrated by the Bahamoldez case above.

To a lesser extent, most cases filed with the court have been initiated based on the refusal to surgery, for instance, the unwillingness to have a limb amputated as a result of severe chronic diseases such as diabetes, or refusal to use technology that extends life artificially (ranging from mechanical ventilators to methods of artificial hydration and nutrition). Among these cases, which started to be judicialized from the 2000s, the most relevant cases are those in which relatives claimed for the suspension of ongoing medical treatment and those in which individuals resorted to court for preventive purposes, so as to avoid the performance of such procedures in the future. These dissimilar cases are illustrated, on the one hand, through the complaint filed by a man requesting physicians to suspend the artificial nutrition and hydration to his wife who was in vegetative state, (39) and, on the other hand, through the complaint of a woman suffering from a degenerative disease who required professionals to respect her refusal to undergo invasive procedures.(40)

Most cases are handled in court when patients are either critically ill (due to an accident or an advanced stage of disease) or in the end stage of a chronic or degenerative disease. At this stage, the requests directly seek to allow for an imminent death to occur as a result of the withdrawal of life support or the non-performance of the urgent procedures. To a lesser extent, individuals resort to court in situations where the end of life is not imminent, such as the claim submitted by the parents to a minor who suffered from a degenerative disease to prevent the performance of any invasive treatments in the event of a future health crisis that may risk patient's life.(41)

It should be mentioned that none of the cases handled in court refer to medical procedures related to euthanasia or assisted suicide, medical practices punished by the Argentine legislation, which includes, for instance, claims for authorization to perform direct actions aiming to cause the patient's death (for example, the so-called "lethal injections"), as it does occur in judicialized cases in other countries.(42)

A relevant aspect about the judicialization of the refusal to medical treatment is the fact that, during the period analyzed, many rulings were issued because one of the parties had resorted to court for preventive purposes. These claims are generally filed by either health professionals or institutions in order to prevent future judicial claims, or patients, to avoid being subject to unwanted medical treatments in the future. These types of claims are characterized by the request for a judicial authorization in regards to personal decisions that, in accordance with the prevailing legislation, do not require such authorization – such as the already mentioned request submitted by a woman refusing future invasive medical procedures(40) – and even in the cases where there is no dispute over the will expressed by the patient, the family and the medical professionals. A good example of these requests, which show the "preventive" nature of most judicialized cases, is the complaint filed by a private clinic where a judge ruled against the performance of a blood

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transfusion to a Jehovah's Witness patient.(43) The following excerpt from a ruling issued by the Argentine Supreme Court of Justice illustrates this idea:

> In effect, the terms governing such request, which includes an authorization request for the non-performance of blood transfusions, clearly show that there are no conflicts of interest between Z. and the medical institution. Consequently, one of the fundamental requirements to authorize the exercise of judicial authority is not furnished in the case, that is, the existence of "disputes between parties having opposite and personal legal interests for the elucidation on judicial pronouncements."(43)

The enactment of regulations or the issuance of relevant jurisprudence on this subject (such as pronouncements made by the Argentine Supreme Court of Justice) does not necessarily impede the future judicialization of similar cases, as evidenced in the suit that commenced after the enactment of the "Death with Dignity Act" in 2012. Nor in the frequent filing of complaints over the refusal to blood transfusions observed during the period under analysis, after several rulings protecting this right had been issued by the Supreme Court.

Information related to the particulars of the claims or complaints have been presented thus far. Now then: which answers did the court provide to these requests? To what extent and under which circumstances did they rule in favor of the refusal to medical treatments or procedures?

The majority of the sentences collected have guaranteed the right to refuse medical treatment at the end of life. This right is endorsed by any of these three forms: legitimizing the refusal to medical treatment, claimed by either the patients or their relatives(40); supporting the authorization request for the non-performance of medical procedures presented by health professionals or institutions(43); or even refusing the authorization requests submitted by either health professionals and institutions(36) or relatives(37) for the performance of medical procedures rejected by patients. In the cases involving minors, such as the requests made by parents who refuse to allow blood transfusion for their children,(44) only a few judgments have been pronounced in favor of the refusal to medical treatment.

The jurisprudence ruling in favor of the refusal to medical treatment was ratified in the 1990s, when the first constitutional sentences recognized the supremacy of patients' autonomy to decide on their bodies(38) were issued and the framework of the right to a dignified death started to be outlined.(36) The rulings opposing the claims for refusal to medical treatment are grounded in the protection of life as ultimate good. In contrast, the legal basis for decisions that support the refusal to medical treatments varied during the period under analysis.(30) However, these decisions are generally grounded in constitutional rules that guarantee the right to privacy and autonomy (sections 14 and 19 from the Argentine National Constitution); in legislation governing medical practice and patients' rights, such as Act no. 17132 "Medical Practice Act," (45) which forces health professionals to respect patients' refusal to medical treatment; and, after 2012, on Act no. 26742,(2) an amendment to the Patients' Rights Act that was enacted some years before, included more specific references to medical treatments at the end of life.

Justiciability of decision-making at the end of life

The increase in the judicialization of health issues in Argentina has been associated with normative and procedural changes that encouraged litigation on this field, for instance, through the granting of constitutional rank to treaties that explicitly acknowledge the right to health, the inclusion and flexibility of tools that allow access to justice, and the development of structures that support judicialization, such as attorneys-at-law specialized in litigation over certain health-related issues.(18,24,26) Having said that, which are the requirements for the judicialization of the right to refuse medical treatment at the end of life? Which factors have impact on the low levels of justiciability of this right?

The elements that can facilitate or obstruct the processes of judicialization over a particular issue can be those factors found within the legal field, such as the existence or non-existence of regulations and entities supporting litigation, and those found outside this field, such as social and political processes that contribute to approach a particular issue from a perspective of rights.

The normative framework supporting the claims related to the refusal to medical treatments has varied during the period analyzed. Prior to the enactment of the so-called "Death with Dignity Act" in 2012, there was no explicit legal framework for the decisions over the non-performance or suspension of medical treatments that may lead to the patient's death. This act shed light on the scope of the terminal patients' rights, by expressly describing the medical conditions and treatments that may be rejected, in order to prevent the judicialization of patients' decisions regarding the continuity or non-performance of medical treatments. Although the Argentinian regulatory framework had included the right to refuse medical treatment since 1967 in Act no. 17132 ruling over Medical Practice,(45) which already forced health professionals to respect the patients' will in the event of refusal to medical treatment, several legal actors reported the existence of a legal gap in different instances and situations. The lack of clarity of the legislation available during the period analyzed, which did not specify which medical treatments could be refused, who could do it and under which circumstances, possibly impacted on the low number of cases taken to court by patients and their relatives. Furthermore, in a context characterized by the defensive medicine and the fear of medical malpractice lawsuits,(6)[b] this situation contributed to the preventative judicialization promoted by health professionals and institutions aiming to protect themselves against prospective complaints.

The existence and availability of entities providing legal advice in litigation processes over these issues, as may be the case of attorneys-at-law and NGOs specialized in bioethics, also play a role on the justiciability of these rights. In Argentina, unlike other countries, there are no associations intended to promote terminal patients' rights, but the creation of entities providing legal advice on these issues is growing in number. The supremacy of rulings related to lawsuits initiated by Jehovah's Witnesses regarding the refusal to blood transfusions is partially the result of greater legal support for this religious group, either to bring a lawsuit in the event that the decision of a religious follower were violated, or to provide advice and assistance to express an advance directive. Although other health conditions have gathered groups of patients or relatives who have politically strived for the acknowledgement of rights (such as the paradigmatic case of HIV/aids), until 2011, there had not been any kind of movement that grouped or represented terminal patients in Argentina.(3)

Another factor to be considered is what legal experts call the *legal opportunity structure* of prospective plaintiffs, in other words, the fact that the courts are considered the adequate environment and the most operative alternative to have these types of disputes solved.(48) In this respect, the frequently extended times of the judicial processes in Argentina do not seem entirely compatible with the briefer times in which these decisions need to be made. As discussed before, the majority of the complaints analyzed are submitted when the patients are in a critical condition (as a result of an accident or surgery) or in a very advanced stage of a progressive disease, in which time is a limited resource. In this context, justice may be considered a barely operative alternative to have these problems at the end of life solved.

One of the factors that impact on the judicialization of a certain issue, outside the judicial field, is a broader conception of judicialization as a matter of rights.(49) This refers to the extent to which citizens perceive –in terms of rights- the process of decision-making in extreme situations, where personal dignity is at stake, and identify the State as the guarantor for the full exercise of the patients' autonomy under those circumstances. In this regard, the discourse about the patients' rights and autonomy regarding health decisions is relatively recent in countries such as Argentina, where paternalism and informal mechanisms of trust in the medical authority have gained importance regarding these types of decisions.(6)

In Argentina, the public complaints filed by patients and relatives – after the enactment of the "Death with Dignity Act" in 2011 – opened a new means for the political resolution of disputes concerning the medical management of the dying, and these complaints also included the discussion about the patients' right over their body(3) in the public agenda. Prior to this situation, the debates over decision-making at the end of life were practically non-existent, and the judicial rulings already mentioned did not have the press attention that similar cases did have in other countries, which probably has impeded that the refusal to medical treatment be outlined as a matter of rights, or that justice be deemed a space intended to guarantee the patients' autonomy regarding these decisions.

DISCUSSION

The previous lines have outlined the process of judicialization of decisions over the refusal to medical treatment at the end of life in Argentina, as well as the factors affecting the justiciability of such decisions. This process is characterized by: 1) the low level of judicialization of the refusal to medical treatment at the end of life; 2) the low number of complaints filed by patients and relatives as opposed to the great number of complaints filed by health professionals and institutions; 3) the remarkable pro-treatment bias displayed in the complaints, which are mainly filed to obtain authorization for the performance of medical procedures against the patient's will, rather than respecting the patients' right to reject any procedures; and 4) a high percentage of complaints presented for preventative purposes or some others considered unnecessary, since there were no conflicts between the intervening parties (health professionals, patients and relatives) or, in many cases, in the situations where no judicial intervention is required, in accordance with the prevailing legislation and jurisprudence on this matter. The low levels of litigation concerning this right may be associated, among other factors, with the lack of accuracy in the regulatory framework governing medical decisions at the end of life, the non-existence of either legal grounds or associations protecting terminal patients' rights, and the citizens' low level of perception of the refusal to medical treatments as legal matter.

Comparing the features of the judicialization of health-related issues in Argentina with those observed in other countries is a complex task. In general terms, the research studies reviewing the jurisprudence available on this issue are mainly focused on the analysis of judicial decisions from a legal or normative perspective (discussing whether dignified death may be considered a right or not, and which the supporting grounds are), rather than in the complaints originating those decisions and the dynamics through which complaints are taken to court.(32,33,34,35,50,51,52,53) For instance, some reviews of the American jurisprudence account for different issues on which the court has pronounced a sentence. Furthermore, they emphasize the legal grounds supporting these sentences, in relation to issues such as the withdrawal of life support, advanced directives, palliative care and assisted suicide,(51,52) but these reviews neither characterize the litigation processes over these issues nor enable inferences on possible tendencies to be drawn. The bibliography referring to the enactment of laws related to this issue, such as the inclusion of the refusal to medical treatment in the legal framework in Mexico(54) and Andalucia,(55) or the regulation of advance directives in Uruguay(56) discusses the scope and limitations of these rules.

However, both these reviews and the sociological studies that analyze the movements defending the right to a dignified death in many countries(57,58,59,60) provide the keys to put the process of judicialization over medical decisions at the end of life in Argentina into perspective.

An aspect discussed in the bibliography is the impact caused by the lack of accuracy of the regulatory framework – both in terms of medical practice and the justiciability of the refusal to medical treatment. The absence of specific legislation or the misinterpretation of some rules cause uncertainty about which medical treatments may be rejected, by whom and under which circumstances. Even in countries where the right to refuse medical treatment has been expressly included in the legal framework, such as Mexico, by means of the enactment of the General Legislation on Palliative Care and Pain [*Ley General de Salud en Materia de Cuidados Paliativos*], there is no accurate data regarding which treatments may be suspended.(54) A case in Colombia has become paradigmatic, since in 1997 the Constitutional Court legalized some cases where euthanasia was requested and authorized terminal patients to be assisted by a physician to end their lives.(54) The lack of regulation of this practice caused uncertainty about the legal framework for euthanasia, and this is precisely what the current initiatives seek to solve, since there was no clear criteria about the conditions under which this practice could be performed. In the case of Argentina, an act enacted in 2012 sought to fill the gaps existing in the former legislation, explicitly stating the medical interventions that could be rejected, the individuals covered and the procedures required to carry out such practice.

Another problem addressed in the research studies is the role of the entities providing legal support, such as attorneys-at-law specialized in this field and groups or organizations supporting these claims in the litigation process at the end of life. Getting involved or failure to get involved with organizations or groups that defend the terminal patients' rights has an impact on the requirements for the judicialization of medical decisions at the end of life. Unlike some Anglo-Saxon countries, Argentina, as well as most countries in this region, except for Colombia,[c] do not have these types of organizations. The judicialization of complaints filed by terminal patients or their relatives in countries such as the U.S. and the U.K. tends to be initiated and financed by groups of activists gathered in associations aiming to promote the acknowledgement of rights at the end of life. For this purpose, they appeal to the judicialization of these cases and focus on high-impact cases as a strategy to make their claims visible.(42,58,59,60) In the last decades, the debates held in the U.K. about the right to die has been based on judicial cases of high public profiles and organizations such as *Dignity in dying,* which advocate for the legalization of euthanasia and assisted suicide by providing legal advice to individuals seeking to have access to a dignified death.(42,58)[d] Similarly, the organization *Compassion in dying*, which promoted the introduction of amendments by means of referendums to legalize the assisted suicide in several states in the U.S. (such as Oregon, the first state that legalized these medical practices), and simultaneously resorted to court to reach these objectives.(60) Through complaints jointly filed by patients and health professionals, they questioned the constitutionality of the regulations that explicitly prohibited the assisted suicide in some states, but the claims were rejected by the Supreme Court.(60)

This type of support impacts the litigation process in at least two aspects: on the one hand, it influences the demonstration of a litigation strategy, intended to obtain not only individual solutions but also the acknowledgement of the patients' rights.(42,57) On the other hand, the presence of these legal entities impact the extremeness of the complaints filed. In Argentina, there are no precedents of complaints requesting the authorization of practices associated with euthanasia or assisted suicide, as seen in the cases mentioned above.

Finally, the visibility of the claims and debate over medical decisions at the end of life influence the citizens' acknowledgement of these rights. In Latin America, these issues have not been settled as topics for public discussion, only in exceptional circumstances.[e] Issues such as euthanasia, assisted suicide and limitations in the use of life support have not been introduced in the political agenda as forcefully as, to a greater or lesser extent, other sensitive issues, such as abortion. In Argentina, prior to the claim for the enactment of a "Death with Dignity Act" in 2011, filed by patients and relatives, who deliberately eluded the judicial means to have their claims heard, this issue had been practically non-existent in the public agenda.(3) Proper methods for elucidating the impact that the visibility of these private controversies has on health professionals and patients' activities and the impact of the politicization of complaints on the citizens' appropriation of rights at the end of life should be assessed in future inquiries.

CONCLUSIONS

This article has described the judicialization of the refusal to medical treatment at the end of life in the Argentine courts and has addressed the conditions of justiciability of such right. Through the analysis of a set of judicial sentences produced throughout four decades (1975-2015), this article has described the profile of plaintiffs and the judicialized cases, as well as the judicial discretion over sentencing. Furthermore, this article addresses the judicial and extrajudicial factors that may account for the low justiciability of the decisions over the withholding of medical treatment in critical situations where life is at stake.

Some articles analyzing the judicialization advance in the field of health highlight the importance of resorting to court to guarantee the enforcement of rights, while others identify some negative consequences,(21,22,24) which include the introduction of defensive medicine.(6) The unnecessary intervention of courts and judges in the decision-making process seems to be a threat to the health professionals' authority in a practice that, in the past, was not considered problematic.

The low level of judicialization of these types of decisions as well as the importance of medical professionals and the pro-treatment bias of complaints on this issue, which seek to limit the patient's power of decision instead of guaranteeing it, require not only taking more precautions with respect to the implications of the processes of judicialization of medical decisions at the end of life, but also considering to what extent these processes imply either a greater empowerment of patients regarding their rights or a greater potential for conflict in the doctor-patient relation, as may be thought in advance.

In the light of the recent changes in the Argentine legislation and the configuration of the decisions at the end of life as a topic for public discussion nationwide,(3,4,5) it is worth bringing up some questions about the future direction of the judicialization in the field of health: to what extent will a more accurate legislation imply a reduction of these types of cases being filed with the court? Or, conversely, as seen after the constitutional acknowledgement of the rights to health, to what extent will the explicit expression and clarification of these rights increase judicial actions? Will more visibility and politicization of decisions at the end of life contribute to empower patients to demand their rights or will they facilitate the joint decision-making between medical professionals and patients? To what extent will the new legislation change the medical practice and will allow it to ensure the respect for the patients' rights?

An adequate assessment of the impact that the changes in the visibility of the issue and the legal framework will have on the judicialization of the decision-making process at the end of life in the following years, as well as the changes in the effects of these processes on the resolution of conflicts within the medical sphere (between patients, relatives and health professionals), will require research studies that lead to reconstruct the different edges of the problem in its entire complexity. Observing the evolution of the jurisprudence

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on this issue in the following years and examining the attitudes and practices of health professionals and citizens regarding the medical decisions at the end of life will lead to analysis of the real impact of these processes. Finally, comparing the judicialization of the refusal to medical treatment in countries with different legal frameworks and dissimilar experiences in the politicization of claims related to dignity at the end of life will contribute to a better understanding of the factors involved in the configuration of dignified death as a matter of rights.

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ENDNOTES

[a] The legal proceedings that are commenced but do not reach the sentencing stage due to the patient's death during the judicial process, which is usual in this type of lawsuits, make it difficult to quantify with greater accuracy the number of the judicialized cases in this field.

[b] Although there is no accurate statistical data, private surveys reflect the increase in both the malpractice lawsuits in Argentina and the low number of claims that succeed in court.(46) Smulovitz(18) indicates that this gap may derive from the excessive number of complaints taken to court as well as the judges' low willingness to handle such complaints. In this regard, a ruling issued by the Inter-American Court of Human Rights should be cited since, as a result of delays and omissions of the Ecuadorian Justice in connection with a medical malpractice lawsuit, it set a precedent for national states' duty to guarantee the citizens' right to personal integrity in this type of cases.(47)

[c] Colombia is the only country in Latin America that is a member of the World Federation of Right

To Die Societies, an organization that gathers groups of people who actively struggle for the individuals' self-determination at the end of life.(61)

[d] Tony Nicklinson, who suffers from locked-in syndrome, and Debbie Purdy, who is affected by multiple sclerosis, filed a claim with the court sponsored by this organization in request of medical assistance to end their lives. In both cases, the court dismissed the claims.(42, 58)

[e] The exceptions may include the debates on the sentence issued by the Colombian court,(54) the enactment of the death with dignity act in Uruguay in 2009,(56) or the judicial process for the amendment of the Brazilian Medical Ethics Code that enabled the refusal to unnecessary medical treatment in the case of terminal patients.(62)

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