



LAS DIRECTIVAS ANTICIPADAS EN
AMÉRICA LATINA. UN ANÁLISIS ÉTICO
A PARTIR DEL CASO ARGENTINO

AS DIRETRIZES AVANÇADAS NA
AMÉRICA LATINA. UM ANÁLISE
ÉTICO DE CASO DA ARGENTINA

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Advance directives in Latin America.

An ethical analysis with a focus on Argentina

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RESUMEN

En años recientes, las directivas anticipadas (DAs) han sido incorporadas de manera creciente en las sociedades latinoamericanas como un instrumento que permite a los pacientes especificar el modo en que desearían ser tratados en caso de que no sean competentes. El objetivo principal de estos instrumentos es, por lo tanto, incrementar el respeto por la autonomía de los pacientes. No obstante, es importante para ello conocer la experiencia que arrojaron las DAs en otros países, para poder diseñar así la mejor manera de implementarlas. Igualmente importante es identificar posibles facilitadores y barreras que pudiera ofrecer el contexto latinoamericano para llevar a cabo dicho proyecto. En este artículo se analiza la evolución de las DAs en los Estados Unidos, se concentra especialmente en las dificultades que surgieron a lo largo de este proceso, y que se deben fundamentalmente a un abordaje excesivamente individualista del proceso de toma de decisiones. En contraste con ello, se argumenta que el rol importante que desempeñan generalmente las familias, u otras personas cercanas al paciente, en las sociedades Latinoamericanas ofrece condiciones favorables para lograr un abordaje más relacional, capaz de superar los problemas del modelo individualista. Sin embargo, se argumenta también que se necesitan esfuerzos importantes para mejorar la calidad de la relación médico-paciente-familia. En particular, la superación de las acciones paternalistas todavía ejercidas por algunos médicos, frecuentemente en conjunto con los familiares, constituye una condición necesaria para la implementación de las DAs.

Palabras Clave

Directivas Anticipadas, América Latina, Argentina, Ética y Cultura.

SUMMARY

In recent years, advance directives (ADs) have been increasingly incorporated into Latin American societies as an instrument that allows patients to specify how they would like to be treated in the event that they are no longer competent. Their main goal is, therefore, to increase respect towards the autonomy of patients. However, learning from the experience yielded by ADs in other countries, in order to work out the best way to implement them is important to achieve this end. Identifying potential facilitators and barriers to carry out such a project that can be found in the Latin American context is also important. In this article, we will analyze the evolution of ADs in the U.S., focusing especially on the difficulties faced during this process which arise mainly from an overly individualistic approach to the process of decision-making. In contrast, we will argue that the role usually played by families or other people close to the patient, in Latin American societies offers favorable conditions to implement a more relational approach, able to overcome the problems encountered by the individualistic model. Nevertheless, we will also argue that significant efforts are needed to improve the quality of the physician-patient-family relationship. In particular, overcoming the paternalistic actions still exerted by some physicians, often concerning relatives, constitutes a necessary condition for the implementation of ADs.

Keywords

Advance Directives, Latin America, Argentina, Ethics and Culture.

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RESUMO

Nos últimos anos, as directivas de avanço foram incorporadas cada vez mais nas sociedades latino-americanas como um instrumento que permite aos pacientes especificar o modo em que gostaria de ser tratado quando eles não são competentes. O principal objectivo destes instrumentos é então aumentar o respeito pela autonomia dos pacientes. No entanto, é importante conhecer a experiência de avanço de políticas em outros países, para projetar a melhor maneira de implementá-las também. É importante também identificar potenciais facilitadores e barreiras que poderiam oferecer o contexto latino-americano para realizar este projeto. Este artigo discute a evolução do avanço de políticas nos Estados Unidos, especialmente focando as dificuldades que surgiram durante o processo, e que é devido primeiramente a uma abordagem excessivamente individualista do processo decisório. Em contrapartida, defendemos que o papel importante que as famílias, ou outras pessoas próximas do paciente nas sociedades latino-americanas, geralmente oferece condições favoráveis para alcançar uma abordagem mais relacional, capaz de superar os problemas do modelo individualista. Também discutimos a grande necessidade de esforços para melhorar a qualidade da relação médico-paciente-família. Em particular, a superação das ações paternalistas exercidas por alguns médicos, muitas vezes em conjunto com membros da família, constitui uma condição necessária para a aplicação das directivas de avanço.

Palavras-Chave

Diretivas antecipadas, América Latina, Argentina, ética, cultura.

INTRODUCTION

The increasing use of medical technology capable of extending life, sometimes in circumstances under which many would rather die, has prompted important ethical questions about the place of patients in the process of decision-making. The case of incompetent patients who did not express their preferences for care while they were still able to do so is particularly challenging. In Argentina, the case of *M.d.C.s.* illustrates the difficulties that may arise in such situations very well. Despite her husband's requests to withdraw artificial feeding and hydration after she had remained five years in a vegetative state, the Supreme Court of Justice of the Province of Buenos Aires ruled in 2005 that doctors must keep her alive because "there is no present or past expression of the will of the patient" (Suprema Corte de Justicia de la Provincia de Buenos Aires, 2005, 114). According to the judges, even if it can be argued that the best interests of a person in a vegetative condition is to die with dignity, only people themselves can give up their right to live. This was legally justified, they asserted, since "life is the first right of the human person that is recognized and guaranteed by the National Constitution" (Suprema Corte de Justicia de la Provincia de Buenos Aires, 2005, 25). Similar to the very well-known case of *Nancy Cruzan* in the United States, the judges followed a very demanding rule that requires continuing treatment unless it is demonstrated with a *high level of certainty* that the patient would have chosen otherwise (Kadish, 1992). Moreover, the judges, drawing also on the experience of the United States, stressed the need that patients state their treatment preferences beforehand by means of an AD.

That same year, the School of Notaries of the Province of Buenos Aires, prompted by a growing number of similar cases, launched the Registry of Acts of Self Protection where patients can issue written ADs (De Brandi, 2009). The case of *M* has been widely commented on as a successful example. *M*, after being diagnosed with a neurodegenerative and irreversible disease, signed an AD refusing life-sustaining treatments. However, given that there was still no law in Argentina that explicitly mentioned these documents, her husband further submitted the case to a local court to ensure that doctors would be compelled to follow her instructions (Ferrari, 2005). Although ADs were already supported, even if not mentioned, by previous legislation, it was not until 2012 that these instruments received full

legal recognition through the Regulatory Decree 1089/2012 of the Law on the Patients' Rights in their Relationships with the Professional and Institutions of Health passed in 2009 (Law No. 26.529), and later modified by the Law on Death with Dignity passed in 2012 (Law No. 26.742) (Boletín Oficial de la República Argentina, 2012).

The legal recognition of ADs in Latin American societies is certainly an important step forward in the process of increasing respect towards patients' autonomy. However, the remaining task is to achieve the effective implementation of ADs in these cultural settings. In this article, we will analyze the evolution of these instruments in the U.S. in order to identify the difficulties faced in that country since they were first developed, and the reasons that may explain those difficulties. We will also discuss an alternative approach to ADs based on a relational approach to the process of decision-making which, although already stressed by many authors in the U.S., could not yet be implemented there mainly due to the dominant cultural traits of their society. Finally, we will examine the prospect of carrying out such an alternative approach in a Latin American setting, with a special focus on empirical research recently published in Argentina.

ARGENTINIAN LEGISLATION ON AD

Before proceeding to our analysis, we will provide here a brief account of the Argentinian legislation on ADs, which is going to be useful throughout the remaining sections of this article.

The legal requirements placed by the Law on the Patient's Rights to consider a written AD legally binding (Boletín Oficial de la República Argentina, 2012) are an important issue. These can be summarized in four points. First of all, the person issuing a directive must be competent and of legal age. Secondly, their instructions must not violate other laws – for instance, active euthanasia is currently forbidden. Thirdly, "the declaration of the will must be formalized in writing in the presence of TWO (2) witnesses, before a notary public or a competent judge of first instance" (Boletín Oficial de la República Argentina, 2012, 10). Finally, the actual circumstances must (sufficiently) match the situation foreseen by the patient at the moment of issuing their instructions. This last point is particularly relevant since, having been made in advance, the possibility exists that new circumstances arise that the patient did not foresee and that might have changed their mind had they anticipated them.

Another relevant aspect is to distinguish between two types of ADs that the law allows. The first of them enables patients to exert a more direct control over their future care by specifying the medical procedures that they consent or reject. This type of AD is usually known in the literature on medical ethics as a “treatment directive” or “instruction directive.” In addition, the law also allows patients to authorize others to make decisions on their behalf, in which case “[the patient] must designate them in such instrument, and these must certify by signature their consent to represent him” (Boletín Oficial de la República Argentina, 2012, 11). This second type of AD is known as a “proxy directive” in order to differentiate it from the former type. However, as we will see, the main role granted to ADs since they were first developed in the U.S. has been offering patients an effective way to issue choices about specific treatment by means of treatment directives.

THE CULTURAL ROOTS OF ADS AND THE RELATIONAL TURN

The liberal ideal of self-determination is a strongly established one in U.S. culture which has long been enforced by the law (MacLean, 2006). Hence, the idea that patients should be allowed to make their own decisions through every step of the way has been conceived here for a long time as a major task of bioethics. This “autonomy paradigm,” as it is sometimes called, was powerfully driven by courts during the 1950s and 1960s, by ruling that patients have a legal right to consent or reject medical interventions (Faden & Beauchamp, 1986). In order to implement this right, the courts also demanded that physicians provide their patients with all the information they need to make properly informed decisions. In this way, the long-lasting Hippocratic tradition of hiding information from patients and excluding them from the process of decision-making, supposedly for their own sake, was replaced by an empowerment movement aimed at securing the patients’ right to choose the extent and type of care they would receive. In the specific area of end-of-life care, which is our main interest here, this transformation has been strongly fueled after the advent of new medical technologies since the 1960s that could prolong life without necessarily restoring the patients’ quality of life (Jennings, 2012). An impersonal medical care, guided by a reductionist imperative to keep patients alive by all means, led to misuses of this technology that significantly worsened the process of dying due to aggressive interventions

not authorized by patients. The gradual awareness of this reprehensible situation was a key factor for the realization that physicians have a moral duty to seek authorization from patients before applying a medical intervention.

The empowerment movement was certainly critical to increase respect towards patients’ autonomy, notably crystallizing in the now usual practice of informed consent in the U.S (Beauchamp, 2011). However, despite its important achievements, it has also shown a less charitable face, even for societies with liberal goals. The core value underpinning the U.S. ideal of self-determination has been that of self-sufficiency as opposed to mutual dependence. Admittedly, it could hardly be denied that being able to do certain things on one’s own is a good thing, and sometimes even necessary. However, turned into the utmost of all values, the pursuit of self-sufficiency overshadowed the value of social relationships, leading to a strongly individualistic concept of the person, who was largely reduced to a bearer of interests in need of protection against the interference of others (Sanchez-Gonzalez, 1997). In this context, laws were put into place which took precedence over the quality of social interactions and their effects on the process of health care. As a result, end-of-life decision-making has been mainly framed as a matter that almost exclusively concerns patients. In fact, the empowerment movement has been very suspicious of family members who were often seen as obstacles to patient’s autonomy (Nelson & Nelson, 1995). Therefore, against the essentially individualistic background of this movement, constructive engagement of families in the process of decision-making did not get as much attention as the development of new devices designed to increase self-determination.

Part of the empowering movement was also the creation of ADs forms, which came into force definitely in the U.S. in 1991 through the Federal Patient Self Determination Act. Faced with the fact that an increasing number of patients were incompetent by the time medical decisions had to be made, usually due to a neurological disorder, there seemed to be no reason not to enable patients to make decisions in advance by means of a legal document. This would be not only possible – at least for some situations – but, most important, perfectly consistent with the highly appreciated value of self-sufficiency. Put in other words, ADs forms were created to meet the dominant values of the U.S. culture “which places a high premium on self-reliance,

individualism, self-determination, and control of one's own destiny" (Pacquiao, 2001, 27). Therefore, following the lines of the empowerment movement, issuing an AD was mainly conceived as an individual activity. Accordingly, family members were generally not involved in the process of decision-making, which led to several problems. Because many patients had never spoken about their preferences with their families, who learned about the existence of an AD once the patient was already incompetent, conflicts arose between relatives and physicians about the exact interpretation of the patient's wishes (Jennings, 2012). This not only created more distresses among caregivers, but could also render ADs powerless. In addition, as the complexity of clinical scenarios increased, treatment directives were often too rigid to guide medical decisions. In these cases, family relatives with a good knowledge of the patient's perspective about the process of health care could have provided the flexibility needed to interpret the patient's wishes in light of the current information. However, a third problem arose even in the presence of proxy directives. Although the patient had designated a surrogate, it was not possible to infer what the patient would have wanted – an exercise of substituted judgment – since the patient had never spoken about those issues with the proxy. As a result, the benefits of any type of AD, whether it was a treatment directive or a proxy directive, turned out to be much more limited than was expected.

In response to this situation, many authors in the U.S. have already stressed that the completion of ADs forms should be part of a broader process of advance care planning (ACP) that incorporates the patient's social environment (Martin et al., 2000; President's Council of Bioethics, 2005; Levi & Green, 2010; Jennings, 2012). This relational approach, as opposed to the individualistic model, emphasizes verbal communication between doctors, patients and families in order to achieve a common understanding of the goals for health care. Moreover, while not rejecting the potential benefits of a written document, ACP does not necessarily lead to the completion of an AD form. However, the dominant cultural features of the U.S. has made this program very difficult to implement, and issuing ADs there still consists largely of an individual activity whereby patients formalize their preferences in a legal document without the involvement of families or other people close to them.

ACP IN A LATIN AMERICAN SETTING

In contrast to the U.S, Latin American societies are less individualistic. Self-sufficiency is not the ultimate goal here, and radical independence from the social environment is, therefore, generally not perceived as a desirable end either. On the contrary, too much emphasis on self-sufficiency, rather than being perceived as empowering, is often viewed as weakening people by isolating them from those on whom they depend. Possibly due to their Mediterranean heritage, Latin Americans usually place a lot of emphasis on the virtues they expect from their physicians and people close to them too, such as trustworthiness, solidarity and compassion (Gracia, 1993; Sanchez-Gonzalez, 1997). As a result, far from an individual endeavor, life is mainly experienced here, though not without many conflicts, through interpersonal relationships intended to elicit attitudes and actions of mutual care (Pessini & Barchifontaine, 2000). Everyday matters are usually shared, as a minimum, within the private sphere of the family, and, as issues become more serious, the involvement of loved ones typically increases too. Similarly, diseases, especially when they are more severe, are not seen as a problem affecting only one individual, but a matter of great concern also for those close to the patient. Accordingly, responsibilities for end-of-life decision-making normally include family members, who may sometimes even take the leading role (Correa, 2006).

The fact that Latin America displays cultural traits that are highly responsive to the social environment suggests that these societies are well positioned to carry out a more relational approach to ADs. Although there is not much empirical data on this topic, some empirical research supports this hypothesis. In a qualitative study on patients' perspectives recently published in Argentina, those who regarded these instruments as valuable in the process of health care generally granted a key role to their relatives too, who were seen by many patients as the main speakers to whom to communicate their preferences (Mattiussi et al., 2009). Therefore, whereas the dominant cultural features of the U.S. have made it very difficult to implement a relational approach framed within the concept of ACP which would allow one to overcome the problems faced by the individualistic components of the empowerment movement, a majority of patients in this region might actually see such an approach as the natural way to deal with these decisions. Nevertheless, an additional

reason that contributes to the explanation why patients in Latin America may grant a significant role to their families in the process of decision-making calls for important improvements in the quality of patient-physician-family relationships. In the aforementioned study, some patients felt very uncomfortable with the idea of formalizing their preferences in an AD form, instead of delivering their AD *verbally* to their family relatives. One explanation for this attitude is that a written document might be seen as too cold, impersonal and unnatural, due to the role usually played by families. Besides, notary requirements and involvement of witnesses might be seen as unnecessarily burdensome in the presence of trusted caregivers. However, a major reason against the completion of an AD form for many patients in this study was that physicians or health-care institutions could misuse these documents either by actively precipitating the patient's death or by withholding or withdrawing treatments too early. These fears point to a main feature of Latin American societies, namely, the weakness of the rule of law, which has failed to infuse trust in people towards the institutions responsible for enforcing their rights (Pinto & Flisfisch, 2011). Such institutions include health-care facilities as well as the medical profession. Thus, participation of family members in the process of decision-making should also be assessed within this broader social context where families have historically taken on the responsibility to protect their loved ones from potential abuses inflicted upon them. Therefore, significant efforts are needed from physicians, health-care institutions and other relevant parties to address this serious situation by ensuring that the patient's rights are respected. Even though completion of an AD form is not mandatory in the process of ACP, it can be very helpful in some circumstances, and patients should feel confident to issue them if they wish. Moreover, lack of trust towards health-care professionals is contrary to the kind of patient-physician-family relationship required by ACP.

PATERNALISM, STILL A BARRIER TO ACP

While the empowerment movement was already introducing changes in medical practice in the U.S., under the autonomy paradigm, physicians in Latin America were still working mainly under the traditional paternalistic model, which places more weight on the duties that arise from beneficence than on the patient's right to self-determination (Mainetti, 1995; Kottow, 1996; Salles, 2002). This situation

has certainly been undergoing substantial transformation in the past few years towards an increasing respect for the autonomy of patients, and important improvements have been achieved. Legislation on ADs is one of such improvements. However, this is still an unfinished project.

In a study carried out in Argentina which showed that only 22% of terminally ill patients knew their prognosis and 57% were aware of their diagnosis, the authors concluded, without a thorough examination of the patients' perspectives, that self-determination is an Anglo-Saxon value whereas Latin Americans prefer instead to delegate end-of-life decisions to their caregivers (Dimant et al., 2007). In support of this claim, it is often argued that patients give their consent, though implicitly, to such a process of decision-making by not offering any resistance to it – which mainly means not requesting information about the disease or the available medical procedures spontaneously. As an illustrative example, in another piece of research, also published in Argentina, older physicians of patients with Alzheimer Disease were very reluctant to discuss ADs with still competent patients because, they said, there is an implicit agreement, also endorsed by patients, according to which family members are the ones responsible for decision-making with the aid of doctors (Mattiussi et al., 2012). Although advocates of this view do not necessarily reject ACP altogether, they generally hold that physicians in Latin America should not discuss end-of-life issues with their patients unless the latter explicitly request to do so in the first place. According to them, far from neglecting autonomy, a process of decision-making that does not involve patients, but which is not resisted by them either, would stem from patients' preferences deeply rooted in Latin American cultural values. However, there are two main grounds upon which this line of reasoning should be rejected.

The first one, which is mainly a conceptual one, is that taking lack of resistance to the process of decision-making as an autonomous consent, without any further assessment, puts autonomy at a high risk by not placing any serious requirement on how patients arrive at the decision not to resist that process. Instead of relying on reasonably good evidence that the patient autonomously wishes to take no part in the process of decision-making, there is an assumption that the choice not to request information or claim more participation is perfectly autonomous. However, some conditions should be fulfilled to regard a decision as reflecting

the patient's values and beliefs. Widely accepted among them are the patient's competence to consent, the availability of sufficient information, and the absence of controlling influences (Vollmann, 2000; Appelbaum, 2007; Beauchamp & Childress, 2009). It is especially important in Latin America, where fear to question authority is not unusual – probably due to a long tradition of authoritarianism that also includes medical paternalism – to assess that the patient is not influenced to accept a subordinate role by an irresistible fear that their caregivers might turn against them if they choose otherwise (Salles, 2002). Put in broad terms, the person might actually feel alienated from their decision not to resist the process, i.e. they might experience a strong negative feeling relative to it, even if they remain silent about it (Christman, 2004). In addition, choices can also be impaired as a result of inaccurate information of, for example, the consequences that may arise if the patient does not state their preferences. Therefore, taking patients' lack of resistance as an autonomous consent, though an implicit one, when highly important values

might be at stake, is not consistent with the efforts dem-

anded by respect for autonomy. It rather mirrors a paternalistic attitude, which still persists in Latin American societies, where families and physicians often hide information from patients, excluding them from the process of decision-making, without asking about their preferences first (De Siqueira, 2008). In order to avoid paternalism, while also respecting those who may prefer to delegate these decisions to others, physicians should foster a trustful environment to explicitly discuss with patients whether they would like to be informed and to participate in the process of decision-making.

The second reason to reject the argument against actively discussing ADs with patients denies the general claim that Latin Americans do not wish to be involved in decisions about the end of life. Indeed, empirical research shows that the picture is a lot more complex than is sometimes believed. Therefore, generalizations may be oversimplifying, failing to meet individual preferences, even if, as we have discussed, patients do not say so. Some evidence supporting this claim comes from studies carried out on Latin American immigrants living in rich countries (Searight & Gafford, 2005; Thomas et al., 2008). One study, for instance, showed that 48% of Mexicans living in the U.S. do not believe that patients should be told of a terminal prognosis, and 41% believed that patients should not make decisions about life-supporting technology (Blackhall et al.,

1995). Although these figures are often used to show that self-determination is not so important in Latin American societies, it should, nevertheless, be noticed that a significant proportion of the respondents would support patients' participation in the process of decision-making. Moreover, in research recently published in Argentina, 86% of participants said that they would prefer to participate in the decisions concerning their own health, whereas only 10% would choose not to be even informed if they were seriously ill (Borracci et al., 2012). However, consistent with the cultural account provided earlier, respondents often granted some role to their families too. As for ADs, we have already mentioned a study developed in Argentina which showed that some patients would be interested in issuing treatment preferences in advance (Mattiussi et al., 2009). Moreover, this interest increased as they improved their understanding of ADs, although, as we have also discussed before, family members were seen as the main speakers to whom to communicate their preferences verbally.

CONCLUSIONS

Latin American societies are increasingly committing to respect the autonomy of patients, and legislation on ADs is a significant part of this process. However, the mere existence of laws authorizing patients to issue medical decisions in advance, important as they are, does not ensure that ADs will be properly implemented. Hence, it is necessary, on the one hand, to work out the right way to use these instruments in clinical practice, and, on the other hand, to identify potential facilitators and barriers that might be encountered in these specific cultural contexts. Regarding the first issue, a detailed analysis of the evolution of ADs in the U.S., which shows that poor outcomes arise from an overly individualistic approach to the process of decision-making, strongly suggests that ADs should be incorporated into a broader relational approach to end-of-life decisions. Therefore, provided that patients do not refuse, families or other important people, besides physicians, should participate in the deliberative process of ACP. As for the second issue, the fact that Latin American societies traditionally grant an important role to caregivers in the process of decision-making, which is expressed through a more family-centered model, suggests that these societies are well positioned to implement such a relational approach. Nevertheless, efforts are needed to improve the quality of the physician-patient-family

relationship. This entails, in addition to the good communicative skills of physicians, increasing trust towards health-care professionals and health-care institutions by showing more respect for the needs of patients and their own views about the process of care. Overcoming the paternalistic actions still performed by some physicians, often along with families, which constitute a necessary condition for the implementation of ACP is especially important.

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