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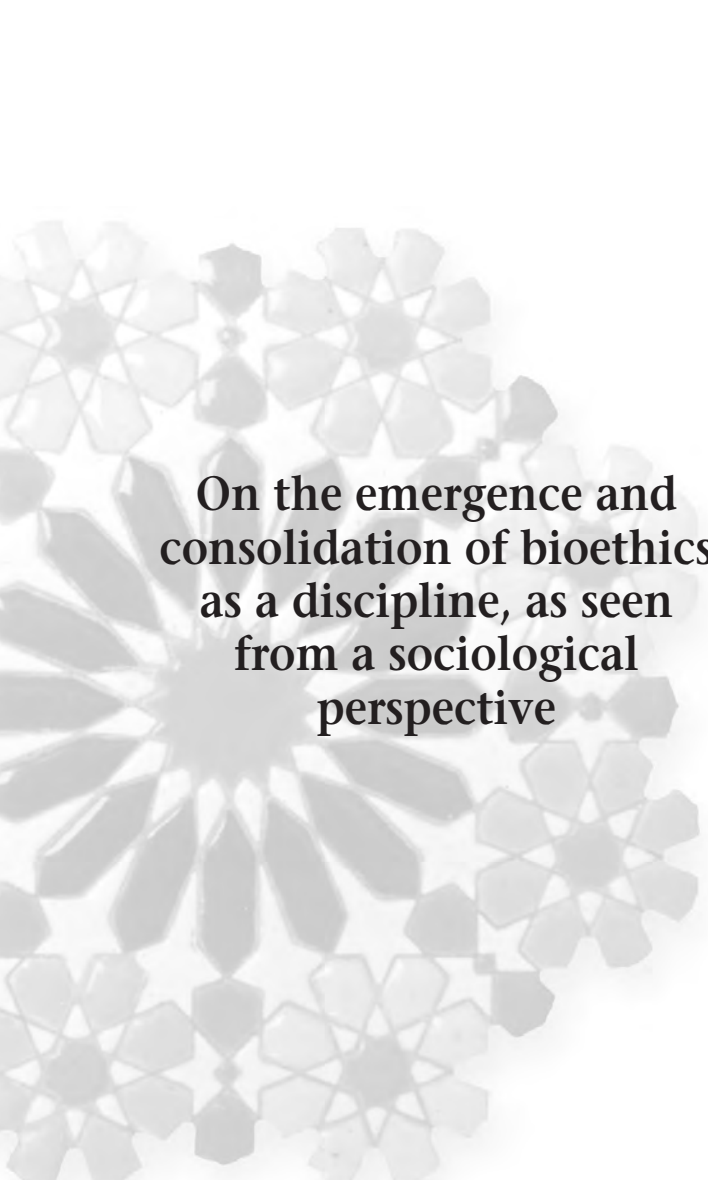
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# On the emergence and consolidation of bioethics as a discipline, as seen from a sociological perspective

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## Abstract

This article examines the emergence and consolidation of bioethics as a discipline from a sociological perspective. This reconstruction helps us to understand on the one hand what is meant by bioethics and what its practices and areas of inquiry are, and on the other to identify various concepts and expert opinions about what the field of study for bioethics should be, opinions which lead in practice to different applications of the discipline in health sciences. This becomes relevant for epistemological discussions about the discipline and for consolidating a sociology of bioethics in the context of Ibero-America.

Keywords: bioethics; history and sociology of bioethics; history of the discipline of bioethics.

This article deals with the emergence and consolidation of bioethics as a discipline. Within the framework of the historical sociology of bioethics (De Vries, 2004), it seeks to reconstruct various origin narratives that imply different concepts of the discipline. I will not offer a substantive definition of bioethics here, since I found that it can have different meanings and is still under discussion within the field itself (Diniz, 2008).

The reconstruction of these narratives helps us understand the assumptions in specific areas of the literature about the practices and fields of inquiry of bioethics. The data presented here are the product of a wide-ranging five-year research study (2008-2013) that combined qualitative methodological strategies from the interpretive paradigm of social studies (Vasilachis, 2006). The principal techniques used were the analysis of written documents (I analyzed a body of 502 texts, including scientific papers, local and international legislation, academic programming at universities and news articles), in-depth interviews of specialists (I conducted 52 interviews of bioethics specialists and members of hospital committees in Argentina) and participatory observation in specialized graduate courses for certification in bioethics, as well as academic conferences in the discipline (I took four complete graduate courses at universities in Argentina and analyzed fifty talks on bioethical topics).

For this article in particular, in terms of methodological strategy, I focused on document analysis (Valles, 2000). I followed the criteria proposed by Belinchón, Ramos and Bellver (2007)<sup>1</sup> for bibliographic surveys of bioethics topics, taking into account statistics on web sites, books, journals and frequently-consulted topics relating to bioethics, along with citation patterns, indexing and referencing as proposed by Holm and Williams-Jones (2006).<sup>2</sup> Based on this analysis, I argue that there are multiple origin narratives that coexist in a kind of amalgam; they involve different definitions and practices and have caused some authors to speak of “bioethics” as a plurality (Gaines, Juengst, 2008; Engelhardt, 1996).

This situation leads certain theorists to conclude that bioethics is not a scientific discipline or a global field of inquiry because it does not possess a unified method, clear rules for citing authors at an international level, access to the same text books on all international circuits (“canonical” texts or authors) or opportunities for undergraduate and graduate training in universities (Holm, Williams-Jones, 2006). Likewise, it has been pointed out that one of the characteristics of bioethics is that it is a multidisciplinary endeavor. This undermines the likelihood of its becoming a unified scientific field and it therefore remains in a “pre-science” stage. These views, based on positivist premises (Schuster, 2002), assume that for bioethics to become a “scientific discipline” it must focus on achieving methodological monism, an empirical approach and the same working norms as natural sciences (Jonsen, 2003), ignoring the fact that there are other ways of constructing scientific knowledge in the post-empiricist era (Schuster, 2002).

Treating bioethics as a non-scientific space has given rise to theories claiming that it involves reflecting on moral issues (Salter, Salter, 2007) and that bioethicists are therefore the “New Priests’ of contemporary secular society” and the “contemporary administrators of the sacred” (Memmi, 1996), or a “cabal of moralizing intellectuals” (Holm, Williams-Jones, 2006, p.3). This type of interpretation has led to a significant number of publications in specialized journals by bioethicists themselves, arguing that bioethics is a scientific discipline (Ten Have, 2006). In fact, most works on bioethics begin with the question “What is bioethics?”

(Borrillo, 2011; Luna, Salles, 2008). And at least some bioethicists originally conceived of this body of knowledge as a discipline with its own characteristics, distinct from other academic fields (Callahan, 1973).

Diniz (2008, p.207) argues that bioethics is a field of knowledge at the interface of different disciplines and that therefore one of its characteristics is disagreement among specialists about its epistemological foundations and object of study. Some authors have attempted to outline an epistemological status pertaining to Latin American and Caribbean bioethics (Garrafa, Kottow, Saada, 2005; Garrafa, 2005-2006; Tealdi, 2008; Rodríguez Yunta, 2009), while others propose a broader geographical and cultural framework that would include the whole of Ibero-America (Pessini, De Barchifontaine, Lolas Stepke, 2010). The different approaches all signal a need for the region to generate its own theory, including a bioethics of intervention (Nascimento, Garrafa, 2011), protection (Roland Schram, 2005), human development (Mackinson, Farinati, 2001; Vidal, 2010), narrative (DeSiqueira, 2012), human rights (Tealdi, 2008), gender studies (Diniz, 2008) and poverty and inequality in Latin American populations (Luna, Salles, 2008).

Overall, the various diverse narratives – which disagree on how to define bioethics – concur that the discipline (or “non-discipline”) emerged at the end of the 1960s in the United States (Garrafa, 2005-2006; Borrillo, 2011) due to developments in life sciences and medicine that led to modifications in ethical and regulatory frameworks in contemporary societies (Velasco Gómez, 2007; González Valenzuela, 2008).

Garrafa (2005-2006) argues that there are four stages in the historical development of bioethics. The first was its foundation in the 1970s, followed by its consolidation in the 1980s, when the discipline spread to Europe and the rest of the world, then the critique stage from 1990-2005 and lastly, from 2005 to the present, a stage of conceptual expansion linked to the Unesco Declaration on Bioethics and Human Rights. I shall now analyze the principal narratives about the origin of bioethics in the United States, narratives that seek to answer the question “What is bioethics?” in the period that Garrafa (2005-2006) identifies as foundational. These origin narratives typically privilege certain historic events and ignore others (Halbwachs, 1994) in the process of constructing a disciplinary memory. Performing this kind of analysis can be useful in terms of understanding developments in Ibero-America, which I shall not be discussing in this article, but which stemmed from, referenced and critiqued the context of the United States. This context is usually assumed to be homogeneous, but as we shall see, American bioethicists themselves had differing concepts of what bioethics is and what it should study.

## **What is bioethics?**

Answering the question “What is bioethics?” is, as I have said, fundamental for bioethicists, whose publications tend to begin by explaining what the discipline studies, when it arose and what issues it deals with. These stories operate as origin myths and provide a framework both for generating theories about bioethics and for the practices that arise from them (Gaines, Juengst, 2008). Each of the different narratives on “the history of bioethics” has implications for the practices and thematic priorities assigned to the discipline (Gaines, Juengst, 2008).

These authors conducted an ethnographic study in which they interviewed the leading figures present at the inception of American bioethics, which led them to reconstruct at least five origin narratives in the context of bioethics in the United States. The reference to the American context is essential, since the different strains of bioethics taught in Ibero-America maintain that the discipline arose in the United States and that an alternative theory is possible if it is formulated independently of developments in the United States (Tealdi, 2008; Pessini, De Barchifontaine, Lolas Stepke, 2010).

Gaines and Juengst (2008) argue that when American bioethicists refer to the origin of bioethics they create at least five stories that can be grouped under three headings: (a) bioethics as reactive, (b) bioethics as proactive, or (c) bioethics as continuity. As regards the first of these, they argue that there are two versions of history. One of them holds that bioethics arose in response to technological developments in the field of life sciences and medicine. In this narrative, new technologies are always a cause for moral concern and therefore we should focus on regulating scientific-technological developments. Depending on one's focus (new reproductive technologies, organ transplants or experimentation on human beings), from this perspective, bioethics is perceived as having a "mission" to respond to the requirements of biomedicine or to monitor biomedicine in society's name so as to guarantee social wellbeing. According to the authors, the second version, bioethics as reactive, argues that the discipline arose as a response to cultural pluralism. It also assumes that bioethics arose out of the challenges appearing in biomedicine, but relates it to the idea of a collapse in the moral values that ought to regulate biomedical sciences. A fresh approach was needed to respond to the newly-emerging ethical dilemmas that traditional medical ethics could not handle. Thus, bioethics should focus on seeking common moral elements on which to base shared decisions about health and biomedical research. Topics of interest to this perspective are abortion, the status of the human embryo, refusal of treatment and bioethics committees as forums for public deliberation (Gaines, Juengst, 2008).

Those who frame the origin of bioethics as proactive (b) argue, firstly, that the discipline arose as a social movement for defending the rights of patients within the healthcare system itself, and secondly, that it arose as a discipline capable of setting limits on future developments in life sciences, in order "to anticipate the biomedical future" (Gaines, Juengst, 2008, p.315). They link the origin of bioethics to the development of various different advocacy movements – for civil, political, cultural, economic, women's and healthcare rights – in the 1960s and argue that the discipline arose as a continuation of those social movements. The bioethicist, from this perspective, is an advocate for patient rights, and participation in hospital committees or governmental commissions must be linked to patient advocacy. Furthermore, bioethics should seek to prevent environmental problems and "anticipate and prepare for such developments in advance" (Gaines, Juengst, 2008, p.319). Thus, one of the main issues from this perspective is stem cell research, genomics and biobanks (Gaines, Juengst, 2008). Although they differ slightly regarding the purpose of the discipline, all these stories (bioethics as reactive or proactive) share the idea that bioethics emerged at the end of the 1960s for the first time in history. The counterpoint is found in the narrative that sees bioethics as a historical continuation (c) of medical ethics and ancient Greek philosophy.

According to Gaines y Juengst (2008), some bioethicists argue that bioethics has a specific lineage and genealogy that is linked on a continuum with the philosophical and ethical values stemming from western medical and philosophical traditions. This narrative claims that bioethics is merely an updated version of traditional medical ethics and philosophy, adapted to the new developments in life sciences and medicine at the end of the twentieth century. In this line of thinking, some bioethicists see the discipline as merely a part of medical ethics and others as a sub-discipline within philosophical ethics, but both varieties situate it within a heritage dating from the ancient Greeks.

All these origin narratives are based on surveys of historical landmarks to illustrate their explanations of the rise of the discipline. The facts mentioned in history texts written by bioethicists reveal their assumptions about the origin and object of bioethics as a discipline. Thus, in their stories the authors privilege the facts they consider important. This mainly reflects the fact that the history of bioethics is being written by practitioners in the field and analyses of bioethics by non-bioethicists remain scarce. I am attempting here to prepare the way for this type of review and analysis of bioethics from outside the field, from a sociological perspective, as De Vries proposes (2004). As an example of the historical landmarks mentioned we can point to the use of the term “bioethics” by oncologist Van Rensselaer Potter (1911-2001) in his pioneering text *Bioethics: bridge to the future* in 1971; many attribute the invention of the term “bioethics” to him (Engelhardt, 1996; Jonsen, 2003; González Valenzuela, 2008). Other landmark events were Henry Beecher’s paper on human experimentation at Harvard University in 1966, the founding of a national bioethics commission by the US Congress [in 1974] and the [New Jersey] Supreme Court ruling permitting artificial respiration to be withdrawn from Karen Ann Quinlan in New Jersey, USA, in 1976 (Rothman, 1991). The first heart transplant (1967) and the abortion debates stemming from the 1973 *Roe vs. Wade* ruling in the United States have also been identified as contributing to the emergence of bioethics (Mori, 1994).

Another issue that features prominently in the literature is the role of Daniel Callahan and André Hellegers, the respective founders of the Hastings Center in New York (1969) and the Kennedy Institute of Ethics at Georgetown University (1971), during this same era (Reich, 1999; Jonsen, 2003). Very few commentators note that Fritz Jahr, a German theologian, had already coined the term “bioethics” in a 1927 article on the relationship between human beings and other living creatures (animals and plants), drawing on the philosophy of Immanuel Kant (1724-1804) (Sass, 2007). Although his was the first recorded use of the term “bioethics,” there are few references in the literature to this theologian’s contributions and it is widely accepted that the birth of bioethics as a discipline can be traced to the end of the 1960s (Sass, 2007). The fact that Jahr was a theologian is part of the reason he is not mentioned as inventor of the term, since one of the characteristics of all the origin narratives (Gaines, Juengst 2008) is that they see bioethics as “a secular discipline based on medical or philosophical traditions, not theological ones” (González Valenzuela, 2008, p.23).

Another recurrent trait of all the origin narratives is the way they separate the discipline from its religious content. Little is said about the fluid relationship between Callahan and Hellegers, both of whom were progressive lay Catholics, with officials at the Vatican (Reich, 1999; Sgreccia, 2007; Lauritzen, 2007), or the role of theologians and priests in early discussions

about dilemmatic cases and their participation in governmental bioethics committees and commissions (Shelp, 1985; Walters, 1985; Smith, 2010; Jonsen, 2006). Nor is the role of Catholic bishops and hospitals in setting up the first bioethics committees mentioned (Craig, 2008). There are references to the fact that early on there were “some priests” involved (González Valenzuela, 2008), but as time went on the discipline became increasingly secular and rooted in the scientific and academic field (Callahan, 1990). Messikomer, Fox and Swazey (2001) argue that Callahan’s vision of bioethics as having a “‘religious-to-secular’ trajectory” is a simplification of events since “Protestant theologians and religionists, such as James F. Childress,<sup>3</sup> Arthur J. Dyck, John Fletcher, Joseph Fletcher, James M. Gustafson, Stanley Hauerwas, Karen Lebacqz, William F. May, Ralph B. Potter, Jr., and Paul Ramsey were the most numerous of the religiously trained persons involved in the early phases of bioethics’ unfolding. Catholic figures included theologians Charles Curran, Germain Grisez, Bernard Häring, and Richard McCormick, laicized priests Albert Jonsen and Warren Reich,<sup>4</sup> and prominent Catholic laymen including Edmund Pellegrino, Daniel Callahan and André Hellegers. The latter two were the respective founders of the first American bioethics centers ... Early contributors to bioethics who spoke and wrote out of Jewish religious traditions were ... Rabbis J. David Bleich, David Feldman, Immanuel Jakobovits, and Seymour Siegel.” (Messikomer, Fox, Swazey, 2001, p.489).

Jonsen (2006) even tells the story of his own and many of his colleagues’ journey from the priesthood to teaching medical ethics, participating in government bioethics commissions and academic conferences in the late 1960s, in the wake of the publication of Pope Paul VI’s encyclical *Humanae Vitae* (1968), which was a fundamental landmark in the emergence of bioethics as a discipline (Ladrière, 1984; Messikomer, Fox, Swazey, 2001). This perspective has been explored further in some studies analyzing the connection between bioethics and Catholicism, an aspect that, along with the development of a personalist bioethics linked to the official doctrine of the Roman Catholic Church (Sgreccia, 2007), does not feature in the various origin narratives.

Another element barely discussed in the narratives compiled by Gaines and Juengst (2008) is the influence of the United Nations Educational, Scientific and Cultural Organization (Unesco), which since 1984 has “play[ed] an important role as a catalyst and think tank, informing public opinion on the human rights implications of scientific and technological progress” (Ten Have, 2006, p.340). In 1991, this organization held its first meeting on bioethics and human rights in Moscow, Russia, and invited specialists from member countries and the United States to coordinate an action plan to institutionalize bioethics worldwide (Ten Have, 2006). The Unesco Bioethics Programme (1993) has helped to develop ethical norms at an international level by issuing declarations (The Human Genome and Human Rights, 1997; Genetic Data, 2003; Bioethics and Human Rights, 2005); by setting up international bioethics committees (International Bioethics Committee, 1993; Intergovernmental Bioethics Committee, 1998) and by creating a global program for ethics education and providing assistance to bioethics committees (2004). In Latin America, Unesco’s Bioethics Network, founded in 2000, is one of the main training resources for bioethicists. Likewise, there are few references to the various declarations of the World Health Organization, especially the



Helsinki Declaration of 1964, which has encountered much resistance from the biomedical and pharmaceutical industry (Tealdi, 2008).

One last element not mentioned in the origin narratives specifically involves bioethics committees, for the direct predecessors of these professional bodies were medical ethics groups responsible for abortions and involuntary sterilization of women in the early twentieth century, and more broadly, their antecedents among the various strains of eugenics at that time in history which urged committees to “apply euthanasia” to human beings considered inferior for racial reasons (Kohlen, 2008). In this regard, some authors argue that bioethics is a discipline which regulates conduct and tends to maintain the status quo, since it does not guarantee to protect people from the abuses of the biomedical system (De Vries, 2004), and that the concepts of human dignity and eugenics in the Nazi era have implications currently for some of the functions of contemporary bioethics (O’Mathúna, 2006).

The hegemonic narratives situate the first committees historically as emerging in the 1960s; they frequently refer to the “God squad” (Jonsen, 2007, p.238), a hospital committee in the United States responsible for deciding which patients would be referred for the new renal dialysis treatment and which would not and would therefore die. I shall not go into any detail here about the specific issue of bioethics committees and their different origin narratives; I focus rather on how academic bioethicists publishing in specialized journals describe the historical origin of bioethics and the issues it deals with. I rely on the work of anthropologists Gaines and Juengst (2008), because they use ethnographic research to show a plurality of origin narratives about bioethics, implying that there are different concepts among specialists of what bioethics should be at the present time. I also point to those elements that are rarely mentioned or not directly named in the construction of the memory narrative (Halbwachs, 1994). This process of retrospective harmonization, characteristic of the creation of any origin story, is performed from the present to give meaning to joint action and provide a frame of reference for the future (Hervieu-Léger, 2008).

Another dimension that helps us establish the different conceptions of bioethics involves the topics covered by bioethicists in specialized journals. We have seen what bioethics is (which in fact implies assumptions about what it should be in the present and the future) according to bioethicists around the world; now we shall take a look at the issues discussed and explored in published texts.

## **What is bioethics about?**

Academic bioethics texts published in the United States cover a wide variety of topics dealing with the legitimacy or illegitimacy of certain practices related to life sciences and biomedicine. They propose arguments for and against presumed ethical dilemmas or even tragic dilemmas (Carnevale, 2007) that require decision-making in which someone will either benefit or lose. These decisions generally involve questions of individual life or death or situations that involve benefit or damage to the health of populations (Pérez Tamayo, Lisker, Tapia, 2007). I shall not analyze the content of the debates on the different issues. I shall explain which topics generate discussion in the discipline, as seen in academic publications, bearing in mind that within each topic there may be different perspectives.



Throughout the survey of specific literature from the late 1990s on, I detected recurrent themes that can be grouped under six discussion headings: (1) what is bioethics (and what should it be)?, appropriate characteristics for a bioethics expert/professional, the role of hospital committees and government/international commissions; (2) stem cell research, assisted reproduction, reproductive cloning, abortion and embryos/fetuses; (3) prenatal tests, genetic screening and its implications for disability and sex selection (prenatal or preconception); (4) intellectual property issues, patents, pharmacology research and drug testing, the creation of biobanks, biopiracy and the “human tissue” market; (5) legal developments and jurisprudence accompanying advances in life sciences and medicine/ the rise of biolaw and; (6) clinical issues in medicine such as treatment refusal, euthanasia, assisted suicide, death with dignity and organ transplants.

All these topics are rooted in the connections between America and European countries, where biomedical research underwent a paradigm shift after the public learned about the first cloned mammal, the famous case of the sheep “Dolly” in 1997 (Valenzuela, 2005) or, in the same period, the development of research on adult and embryo stem cells which heralded the possibility of new therapies (Castagnino, 2005). In this sense, there was more development and production of texts and reflections on the potential of these techniques and less on “doctor/patient relationship” issues or bioethics in hospitals.

Regarding what bioethics actually is (or should be) and the role of bioethicists in contemporary societies, there are, as I mentioned earlier, various points of view. Discussions revolve around characterizing bioethics as applied ethics (Veatch, 2007) and the need to set its limits as a scientific field (Ten Have, 2006). Some also stress that it involves reflecting on the “moral order of society” and that it is a necessary field since politicians do not understand and therefore “need help from experts” to legislate the development, advances and potential future problems created by developments in life sciences (Baker, 2009). In this line of argument, some authors tend to position bioethics as outside politics (Latham, 2002) while others, on the contrary, stress that because it promotes and introduces values and images into public debates, bioethics should be seen as a political activity (Blacksher, 2007). Sádaba (2009) insists that bioethics is “helpful for resolving sociopolitical conflicts,” that this role is usually overlooked due to the “fascination produced by biological advances,” that it must be remembered that “any ethics inserted in bioethics is political,” and that this therefore leads to conflicts of interest (Sontag, 2007, p.175). In this line of argument, some bioethicists stress that regional differences should be respected even within countries themselves and that issues like “the status of the human embryo” should be decided in local parliaments and not via national bioethics commissions (Fosset et al., 2007).

Regarding stem cell research, assisted reproduction, reproductive cloning and, to a lesser extent, abortion, there is a great deal of discussion about establishing the “status of the human embryo.” There are numerous debates about the importance of names, in other words, the issue of whether it can be established (especially in legal texts) that the union of a spermatozoid and an ovum is a “person,” a “piece of property,” a “zygote,” a “pre-embryo” or something else has practical implications in terms of what should be done with “these entities”: whether they should be protected, destroyed, discarded, used for research or tissue transplant (Baker, 2002). One side analyzes the meanings of “fetal potential” and “potential

person,” arguing that it cannot be established that embryos are “full persons in the Kantian sense” and therefore they are “entities with no moral status” (Álvarez Manninen, 2007). The other side insists that “moral status” is held throughout all “our existence” because “life begins at conception” (DeGrazia, 2007) and any experiments with embryos “permanently damage human dignity.” In this line of thinking, in the debates about assisted reproduction there are many reflections on the status of “cryopreserved embryos,” which have not been implanted in a uterus and are kept frozen for later implantation (or not). Some insist on reflecting on the “moral obligations” towards “emerging life,” on how to determine what or who “has life or is alive” (Langstrup, Sommerlund, 2008; Latham, 2002), and on the moral unease that embryonic stem cell research generates in society and public opinion (Majumder, Cohen, 2009). Lastly, some studies discuss the difficulty of drafting public policy on this issue, the rise of a market for human eggs and tissue that needs regulating (London, 2002), and the difficulty of protecting the privacy of data and patenting the results of this research (Chapman, 2009).

Another relevant topic which has generated a significant number of articles involves what is known as “prenatal genetic testing” or “genetic screening.” In this type of research, developments which make it possible to detect malformations or genetic diseases in embryos (Powers, 2001) have led to reflections about whether it is morally legitimate to select the sex of the child one wishes to conceive (Dai, 2001), whether couples have a right to sex selection (Coleman, 2001) and the implications in terms of population and even eugenics of these techniques based on “preconceptual arrangements” (Guichon, 2007). Thus, some writers raise the question of whether it is legitimate to perform prenatal genetic sequencing even though the techniques are available (Donley, Chandros Hull, Berkman, 2012), since it goes hand in hand not only with sex selection in embryos but also with reduction of disabilities or diseases, which leads to defective embryos being discarded in the laboratory or via pregnancy terminations (Anstey, 2007). Some authors maintain that geographic studies have racial and eugenics connotations (Tall Bear, 2007) while others hold that children have “the right to be born free of disabilities and illnesses” (Sabatello, 2009), if the techniques allow this, since there is a moral obligation to create children who have the best expectation of enjoying the most well-being, free of hereditary disabilities or diseases (Savulescu, Kahane, 2009). In this line of thinking, some authors have proposed a new principle for bioethics, that of “procreative beneficence,” but others reject it outright, deeming it illegitimate (Bennet, 2009).

One of the areas of discussion that has generated the most controversy involves intellectual property issues in pharmacological or genome research, drug testing, patents for the results of that research, the creation of biobanks and ownership of the samples held in them, biopiracy and the creation of a market for “human material:” tissue, cells, and blood samples (Iacub, 2004).

Regarding drug trials, it has been pointed out that exposing populations to untested drugs implies benefiting from the vulnerability (both health-related and social) of those who consent to enter a research protocol in the hope of finding a cure for their disease (Grady, 2009). This line of argument critiques the use of placebos, substances with no therapeutic action administered to some of the individual subjects of the study (without their being aware that they are being given an inert compound), to contrast with those who are taking the drug as

part of the trial, arguing that “deceptive placebo use violates patient autonomy” (Barnhill, 2011, p. 219). Others claim that the figure of informed consent, widely debated in bioethics from the beginning, as a document which those who “voluntarily” enroll in research protocols agree to sign, reflects a fair transactional model among free individuals (Miller, Wertheimer, 2011, p.217). There are manuals on how to handle informed consent that indicate how researchers should offer information and what type of communication models should prevail in these types of “transactions;” in order not to enroll individuals under false expectations, the fundamental values should be “accountability and transparency” (Manson, O’Neill, 2007, p.9). Rather than questioning the enrolment of individuals to research protocols, an issue which appears to be resolved with the application of informed consent, some commentators reflect on who owns samples of human material acquired for research purposes (Brody, 2007). Morgan Capron et al. (2009) point to studies indicating that the diversity of international rules and regulations concerning information stored in biobanks (databases that combine biological samples with the results of genetic analysis and health information about the people who provided the samples) and genetic databases (collections/archives of biological human samples used for genetic analysis that can be material repositories of specific diseases with populational data for performing longitudinal studies). The authors indicate that there is a gamut of opinion about who ought to be in charge of these banks and thus become the owner of repositories of information (Morgan Capron et al., 2009). Some authors indicate that this type of data, which also includes biological material from plants and animals, should be considered the “heritage of humanity” and be administered to guarantee “the common good” and that state sovereignty over the “common inheritance” represented by knowledge about genetic data can be a solution to the money-making activities of biotechnology companies, who obtain information from populations so as to market medications to which those involved in the study will not have access (Winickoff, 2007). Lastly, in relation to this topic of discussion, some bioethicists propose the concept of “genomic justice” (Crozier, Hajzler, 2010) and predict the growth of new rights movements for exercising “biocitizenship” (Plows, Boddington, 2006), to confront the process of commercialization of human material and the creation of bioshares markets (Rose, 2007), guaranteeing public and not commercial use of the results of this type of research (Underkuffler, 2007).

The developments in law and jurisprudence that accompany advances in life sciences and biomedicine also appear as one of the topics of discussion in bioethics texts (Casado, 2009) , giving rise to a specific field of knowledge: biolaw (González Morán, 2006). I shall not analyze the specific nature of developments in biolaw, which is intimately related to bioethics and has led to different models of legislation to deal with dilemmas in the field of biomedicine (González Morán, 2006). I will point out briefly that in general it is usually argued that scientific advances are occurring at breakneck speed while the creation of new regulations moves more slowly. There are differences between countries, even though agreements have been achieved on an international level, based on the work carried out by Unesco (Casado, 2009). Among the issues most discussed in biolaw are regulations for research, genetic exceptionality (Rothstein, 2005), cloning (Caulfield, 2003), surrogate motherhood and access to artificial reproductive techniques, euthanasia and assisted suicide (Wolf, 2008), and contracts involving the human body, its parts and tissues (Rao, 2007).

Also, depending on the development of different regulatory frameworks, some raise the question of whether it is imperative, in moral terms, to obey the law and whether doctors and researchers have a “right to conscience” or a “right to conscientious objection” in the face of new legal frameworks that contradict their personal convictions (Smith, 2010).

Lastly, leaving aside more philosophical discussions, there is much coverage, although to a lesser extent than on the issues previously discussed, of topics related to the clinical care of patients in hospital settings, such as refusal of treatment, advanced directives, euthanasia, assisted suicide, “death with dignity” and organ transplants. There are reflections on the differing concepts of death held by patients and the decisions made in practice by health care teams in the final stages of life (Luna, Salles, 2008). Refusal of treatment, non-resuscitation orders, advance directives and the attitudes of the health care team also constitute an area for discussion. To a lesser extent, on the issue of clinical care in hospitals, there are studies exploring the problems of justice and social inequity in health care access for different populations (Furler, Palmer, 2010).

These recurring topics of discussion in contemporary literature on bioethics reflect theoretical, methodological and analytical concepts based on western moral philosophy: Kantian deontology and Utilitarianism (Fitzpatrick, Leach Scully, Baldwin-Ragaven, 2010). This “main branch,” which includes various perspectives on the topics of discussion, takes an approach that marginalizes the interests of women and relegates them to a condition of moral inferiority since, on the one hand, the subject of bioethical analysis generally reflects masculine experience and priorities, and on the other, the epistemological and ontological foundations of bioethics privilege “ways of being and knowing that are masculine” (Fitzpatrick, Leach Scully, Baldwin-Ragaven, 2010, p.3).

In this sense, the texts analyzed present arguments that do not include women as subjects of bioethical inquiry, even though many of the proposed decisions for solving dilemmas involve them. In the case of “the” embryo, the unquestioned protagonist of discussions about stem cell research, genetic screening and abortion, there are no references to women as producers of embryos or egg donors, nor to men’s role as sperm donors or their desire to be fathers (Sparrow, 2008). Few studies provide a gender perspective on the debates about bioethics and biotechnology laws, particularly on reproductive issues or embryonic cell research. In these debates, dominant perceptions about gender and the body affect how the role of spermatozooids and eggs in these processes is understood and the same perceptions about gender and the body are established and updated and relayed to society as a whole as the dominant representations (Schicktanz, 2007).

Since the 1980s and earlier, various women authors belonging to a school of thought called “feminist bioethics,” which itself contains several divergent varieties (Luna, Salles, 2008; Diniz, 2008), have been contributing to the debates from a perspective that focuses on the place of “real life” women in issues relating to abortion, surrogate motherhood, assisted reproduction, genetic research, sexuality, intimate relations and emotions, since women are the social group most affected by regulations that result from bioethical deliberations (Fitzpatrick, Leach Scully, Baldwin-Ragaven, 2010).

Within this approach, there are studies highlighting the role of the state in the emergence of “fetal rights” policies which note that courts, at least in the United States, began issuing

rulings recognizing fetal rights at the expense of pregnant women around 1950 (Daniels, 1996; Morgan, 2009). This politicization of “fetal rights” has shifted public authorities’ focus of intervention onto pregnancy itself, in particular onto regulating the relationship between the pregnant woman and the fetus through the mediation of biomedicine (Daniels, 1996). Likewise, since the late 1990s, embryonic stem cell research and reproductive cloning have led to debates about the moral and legal status of embryos when separate from pregnant women and/or men and women who provide genetic material to be developed in laboratories. Hennette-Vauchez (2008), like Daniels (1996), argues that debates on stem cells made the embryo available as representation. Morgan (2009), on the other hand, argues that this process of considering fetuses as subjects that are separate from pregnant women, egg donors and the social setting in which they are produced, harks back to the development of embryology as a discipline separate from anatomy or biology in the mid-nineteenth century. The author shows that ideas, images, and symbols relating to these miniscule scraps of human tissue can be positioned as separate from the social elements that led to their production thanks to the work of embryologists, who embarked on a process of collecting and archiving embryo specimens so as to analyze the process of human development “from conception on,” helping to make this the principal origin myth of contemporary societies: “we come from embryos” (Morgan, 2009, p.15-17). According to Baker (2002), it was the alliance of Catholicism and nineteenth-century embryology under Pope Pius IX, who declared abortion a crime in 1869, that laid the foundation for the concepts about the beginning of life currently seen in the teachings and doctrine of the Catholic church.

Lastly, a theme that is neglected in reflections about bioethical issues is the relationship between bioethics and religion or theology. Although some authors argue that “secular and religious” disputes can be detected in the bioethical debates found in specialist journals, and that it is important to spell out the place occupied by different religious ethics, since patients’ beliefs can affect whether they decide to refuse treatment or draw up advance directives for medical care (Post, 1991), or lead to conflicts with parents who refuse medical procedures for their underage children for religious reasons. These debates are related to the fact that bioethics should contribute to the pluralism of values in contemporary societies and that in clinical care settings, allowance must be made for the community’s religious beliefs (Craig, 2008). On the other hand, texts often survey the different viewpoints of various religions on a specific topic, such as the beginning of life, showing the diverse concepts on this issue even within Catholicism (Lustig, 2008), or on genetic engineering or the patenting of biological material.

## **Final considerations**

So far I have focused on representations of the emergence and consolidation of bioethics as a discipline which is taught in universities and specialized centers, and which boasts numerous publications with systems of peer review and international indexing. My approach does not involve a substantive definition of bioethics, but rather reconstructs the various origin narratives which imply differing concepts of it. I have focused on the different stories within bioethics in the United States, since that is the main historical referent for the origin

of the discipline in Ibero-American contexts (Garrafa, 2005-2006; Luna, Salles, 2008; González Valenzuela, 2008). The reconstruction of these stories, along with analysis of reference publications on the subject, helps illustrate what bioethicists themselves understand about their practices and field of knowledge. Likewise, I have analyzed how bioethics appeared as a discipline devoid of the religious content present at its inception as a field of inquiry and, with the exception of studies by feminist authors, with no gender perspective. All these viewpoints have influenced the development of bioethics as a discipline in Ibero-American contexts, particularly in Latin America, where various authors are currently attempting to provide an epistemological framework appropriate for bioethics in the region (Garrafa, 2005-2006; Tealdi, 2008; Luna, Salles, 2008).

The characteristic that bioethics adopted as a discipline and which Borrillo (2011) describes as “neotraditionalist metaphysics” is evident both in the origin narratives and in the issues discussed, as we have seen throughout this article, and also in the practice of bioethics in the use of expertise in parliamentary commissions and hospital ethics committees, where certain actors use essentialist arguments in order to present certain issues in bioethics as non-negotiable (Borrillo, 2011). These actors use a disciplinary language that appears neutral, based both on developments in biomedicine and in human and social sciences. It is a discourse that, like religious thinking, demonstrates the abuses of science, the commercialization of the human and the social disintegration produced by modernity (Borrillo, 2011). According to Borrillo (2011), the ideological apparatus used by bioethics in general to limit individual liberties is the notion of “human dignity,” which operates as an imperative principle “imposed on all human beings and to which we must submit.” The author argues that this imperative principle underlies and unifies thinking on “the right and the left.” This configuration of the discipline as a kind of “dogmatism” (Borrillo, 2011) aims, furthermore, to remove a series of issues from political discussion by referring them to the experts to evaluate, issues such as single parenthood, surrogate motherhood, post-mortem insemination and the right to “death with dignity” (Bantigny, 2011). A common characteristic of the “metaphysical” branches of bioethics is that they consider “freedom to dispose of one’s own self” as necessarily a form of commercialization of the body, a form of slavery (Borrillo, 2011). This is seen, for example, in the case of surrogate pregnancies, which are always presented as a form of alienation and reification of women’s bodies, and also in therapeutic rationales for limiting access to reproductive technologies (Ogien, 2010; Hauray, 2010). Borrillo (2011) argues that this perspective comes from the same place as religious traditions and, because the state usually privileges the position of the Catholic religion (Esquivel, 2009), that the struggle against modernity and the individual’s “freedom to dispose of him or herself” reappears in modern form in bioethics, turning human beings’ bodies into a public space to be controlled (Borrillo, 2011) or, in Segato’s words (2008), a territory to be occupied. In this regard, some authors argue that bioethics is a place where the forces of contemporary biopower can be seen (Fassin, Memmi, 2004; Rose, 2007; Fassin, 15 maio 2012). The relationship between bioethics, biopower and biopolitics has not been analyzed in this article and remains to be studied in the future. My goal was to survey different origin narratives and the multiplicity of topics covered by bioethics in the context seen as foundational (the United States), pointing out that even in America there are different views of bioethics’ object and purpose. I believe that



this overview provides a contribution to the field of Ibero-American bioethics, which tends to refer to the context of the United States as a homogenous foundational site, and can also help consolidate a field of sociological studies of bioethics. As De Vries (2004) says, we need to advance from sociology within bioethics towards a sociology of bioethics.

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#### NOTES

<sup>1</sup> Following the bibliometric criteria proposed by the authors, I performed a database search at the library of the University of California Santa Barbara for printed books and articles in scientific journals in the Medline, PUBMED, JSTOR, BMC Muse databases using the keywords “Bioethics\*” or “religion” “history” or “origins.” This yielded a total of over thirty thousand studies, of which three hundred referred to bioethics. In order to survey the themes dealt with by bioethics, various publications were used as reference sources, such as *The American Journal of Bioethics*, *The Kennedy Institute of Ethics Journal*, *The Hastings Center Report*, *The Journal of Law, Medicine and Ethics*, *Philosophy, Ethics and Humanities in Medicine*, *BMC Medicine*, *BMC Medical Ethics*, *International Health and Human Rights*, *The Journal of Clinical Ethics*, *Perspectives in Biology and Medicine*, *Technology in Society*, *Journal of Medicine and Philosophy*, *Social Studies of Science*, *Configurations*, *Genomics*, *Society and Politics*, *International Journal of Feminist Approaches to Bioethics*, *European Journal of Women's Studies*.

<sup>2</sup> The authors analyze common patterns in English-language bioethics publications, proposing a sociological method to explore and analyze the behavior of the “global bioethics community.” To do so they propose three categories, using accessible public data based on computerized analysis: the web-linking patterns of bioethics institutions, citation patterns for bioethics papers and buying patterns for bioethics books. Based on these categories, one can search author's trajectories, principle publications, academic allies and enemies, recurring themes, and most widely-read books. This is an exploratory methodological proposal that helps identify common or divergent traits in a field of study. The authors agree that English-language bioethics is usually considered a homogenous field but that there are heterogeneities and differences (Holm, Williams-Jones, 2006). In the case of this article, the document search was limited to the most widely cited websites in bioethics in the United States.

<sup>3</sup> The authors' analysis of principlism, a school of bioethics founded by James Childress and Tom Beauchamp, stresses the strong influence of these men's religious convictions in the development of their theory on ethics (Messikomer, Fox, Swazey, 2001, p.485).

<sup>4</sup> Warren Reich was the author of the first *Encyclopedia of Bioethics* in 1978, in which he defined bioethics as the “systematic study of human conduct in the field of life sciences and healthcare, when such conduct is examined in the light of values and moral principles” (Viesca Treviño, 2008).

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