INTRODUCTION

Much has been written about ethical problems in medicine in the Anglo-Saxon world and recently in Europe. However, despite the valuable contributions this literature provides for addressing and analyzing problems, bioethics, unlike pure philosophy, is rooted in reality. Even though societies can share outcomes and theoretical approaches, bioethics presents perspectives that are specific to regions or cultures.

This book examines some of the concerns that pervade Latin American society and tries to offer a different vision of some bioethical problems. It studies a recurrent question concerning bioethical issues: How can a developing society, a Latin society, with vices and virtues that differ from those in industrialized societies, approach these problems? To a greater or lesser degree, the chapters that follow echo some of the concerns of all populations marked by vulnerability, intolerance, authoritarianism, and corruption. They consider the peculiar implications that occurrence in Latin and non-mainstream Western countries can have for some bioethical and research situations.

Before the content and organization of the book are presented, some comments about “vulnerability” and “developing countries” are in order, as such concepts inevitably make up part of the theme and analysis of most of the chapters.

“Vulnerability” is a concept that has only relatively recently been introduced into bioethics. Rosemary Flanigan points out that “vulnerable populations” did not become a keyword descriptor in the official Bioethics Thesaurus until 1997,¹ and most of the bibliography on the subject is from 2000 on.² The word “vulnerability” stems from the Latin vulnerare, to wound.³ There are two facets to this word. Onora O’Neill points out that human beings are persistently vulnerable in ways typical to the whole species, requiring protection by means of justice. In this sense, vulnerability is an expression of the human condition, the fragility and finitude of which has been a topic for many philosophers, especially those working in the continental tradition. In addition, O’Neill explains that human beings may become “deeply, variably, and selectively vulnerable to the action of the particular others and the particular institutions on whom we come to depend for specific or often unavoidable purposes.”⁴ This second facet of the term gives rise to the idea of “vulnerable groups.”

In bioethics, the notion of “vulnerability” has mainly featured in discussions of research ethics. The term has been used in a number of Codes of ethics. However, in the light of the characteristics set out above, it can be seen that it is a broader concept, and it seems an adequate one to address the situation of some people living in deprivation, oppression, and powerlessness—conditions that are all too common for many Latin Americans.

New to bioethics though this concept is, there is an even more recent trend⁵ of diminishing its importance. Some argue against the labeling and
categorization of vulnerable individuals and populations because it “risks viewing vulnerable individuals as ‘others’ worthy of pity . . .” or it “stereotypes them.” I believe it is far more comforting to try to evade and deny these disruptive labels than to acknowledge vulnerability and seriously provide safeguards to avoid the harmful consequences it may have. The notion of vulnerability captures significant aspects of marginalized groups. As the guidelines of the Council for International Organizations of Medical Sciences (CIOMS) rightly points out, it describes persons incapable of protecting their own interests. Ignoring these aspects of some populations in Latin America may be hypocritical. Consequently, a first step is to acknowledge the vulnerability of certain populations and persons, and to try to understand why it occurs and how it may be possible to avoid it. This book addresses this issue by exhibiting the situation of some populations that are incapable of protecting their own interests, such as the illiterate, women in societies disrespectful of their reproductive rights, and research subjects in contexts where resources are scarce.

In considering Latin America and “developing countries,” it is worth noting how difficult it is to characterize these countries. A series of terms will be taken as synonyms: “the South,” “developing countries,” and “non-industrialized countries.” It is clear that these are general terms that do not characterize only Latin American countries; however, all these terms have been used in Latin American political and economic analyses. In such analyses, the term “South” makes reference to some loose geographical regions in the American Continent: the North including the United States and Canada, and the South comprising Mexico downwards to Argentina and Chile. The terms “developing countries” and “non-industrialized countries” should be taken as referring to those countries’ level of economic progress. Victor B. Penchaszadeh characterizes developing countries as not having:

... yet achieved the economic development characteristic of the industrialized nations and, as a result, [they] are generally poor, rely on the production of raw materials rather than manufactured goods, are less urbanized, and lack technological resources.  

Despite these broad common features, this book recognizes and respects the vast heterogeneity that exists across the so-called Latin American countries. The book considers the Argentine experience primarily, and secondarily that of the rest of Latin America. The huge differences between countries like Chile, Colombia, Bolivia, Mexico, Brazil, or Uruguay should also be noted. These countries vary greatly in size and natural resources (compare tiny Uruguay to the immensity of Brazil). The constitution of their populations is also quite different, some having a high percentage of indigenous peoples, and extraordinary and sophisticated cultures (for example, the Aztecs or the Incas);
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others have deep roots in Africa; while in others the aboriginal population was nearly eradicated, and include vast numbers of immigrants from Europe.

Finally, there are Spanish, Portuguese, and aboriginal languages—Guatemala, for example has twenty-two ethnic groups. This gives rise to ethnic, cultural, historic, and social diversity. Consequently, heterogeneity is at the very core of these countries, though they also share many common features. Their societies are generally divided by large differences in class and power, and luxury and misery live side by side. Some can access top healthcare while others live in absolute poverty, without drinking water, and suffer from malnourishment. These huge disparities, along with a common “Latin” tradition, European colonization, and the strong presence of the Roman Catholic religion, serve to characterize these countries. So, even though dissimilarities exist between the countries under consideration, this book will highlight the common ties and the impact these characteristics have on bioethical problems.

The first chapter, written with Arleen L. F. Salles, presents some of the challenges bioethics in Latin America faces today. We identify two main issues. The first is the search for a secular approach to bioethics in a region in which the Catholic Church is strong, and heavily influences any kind of public ethical and bioethical discussion. We defend the need for a secular approach if Latin Americans are to construct a moral language that fits the reality of multiculturalism and religious pluralism. We also discuss the content of bioethics in Latin America. We make a distinction between two kinds of problem: the provocative (stem cell research, cloning, new genetic tests, assisted reproduction) and the boring (allocation of scarce resources, deception and breach of confidentiality, paternalism) and argue that both types are pertinent to a serious discussion about bioethics, be it in a developing or in an industrialized country. We reject the supposition that only industrialized countries should be concerned with the ethical issues raised by sophisticated technology. We take this to be a simplistic view: the latest scientific developments have a real impact on developing countries (given, for example, their slight ability to regulate and monitor).

The first chapter, then, outlines the range of options and content that can be covered from a Southern perspective: nothing is foreign. A question that immediately arises is whether a more specific kind of analysis is necessary to treat these problems. Can “casuistry” take a leading role in such an analysis? Chapter Two, “Cases and Casuistry,” explores the potential of casuistry, or a case-based approach, asking whether it is an adequate theoretical tool for capturing the particularity and context of developing countries. The chapter clarifies the main principles of casuistry and examines the use of cases in relation to bioethical problems. It analyzes the ambiguities that arise in Albert R. Jonsen and Stephen Toulmin’s proposal concerning the scope and importance of cases.

Chapter Three, “Respect for Persons and the Illiterate,” illustrates some sources of concern in the South, amongst them the lack of respect toward patients, patients’ vulnerability, and the intolerance that exists in Southern
societies. The vulnerability of many patients in the region is rooted in the incidence of illiteracy, as evinced in the treatment they receive, their difficulty in making themselves heard, and the strong paternalistic attitudes to which they are subject.

The chapter analyzes one of the most common arguments used by physicians in Argentina and elsewhere in Latin America, an argument that maintains that working with a highly illiterate population necessitates a paternalistic approach. Those who advance this argument presume that their patients are incapable of understanding or making correct decisions. Physicians, it is held, are better qualified to make the wisest decisions, and therefore must do so. This argument leads to an *a priori* attitude toward these patients, which the chapter challenges.

Another social situation the chapter considers extensively is the denial of women’s reproductive rights and the extremely restrictive legal circumstances with respect to abortion. It serves as a backdrop to the following chapters. Based on these restrictions, “Internal Reasons and Abortion” accepts the challenge that an analysis from the Southern perspective implies. It acknowledges the restrictive position of Argentine legislation on abortion and tries to open a path toward a new kind of examination.

I propose an analysis of the abortion issue taking Bernard Williams’s doctrine of internal reasoning as a starting point. I argue that Williams’s views can place the discussion on another level. If the discussion were centered on the traditional assertion about the moral status of the fetus, people would quickly confront two irreconcilable positions: either one becomes a person from the moment of conception and, therefore, an embryo has rights; or, one becomes a person at birth and lacks strong rights until that moment. These are two uncompromising positions. Here, Williams’s “internal reasoning” proposal is explored as a way to providing a more dynamic approach. The chapter proposes that tolerance ought to be exercised, and calls for a dialogue in societies in which this appears to be almost impossible. It argues for the interaction of rational agents who wish to reach a minimum consensus through dialogue, a colossal task in strongly intolerant countries.

In Chapter Five, “To Procreate or Not to Procreate? AIDS and Reproductive Rights,” I question medical paternalism in such a highly controversial issue as that of patients with Acquired Immune Deficiency Syndrome (AIDS) who must choose whether to have a child and risk transmitting this serious disease to their offspring. One of my objectives is to present the theoretical problems that arise when taking these kinds of decisions: situations that range from the difficult choice of whether or not to have a child with disabilities, to the subtle distinctions between harm, wrong, and wrongdoing. Another element is the paradoxical attitude toward reproductive rights in countries in which there is no national law allowing women to be informed, to look after themselves, and to choose when to have children; and, at the same time, when infected women become pregnant they are stigmatized. Until 2002, Argentina did not have a
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federal law for responsible procreation. Its enactment was hindered by strong opposition. Nowadays, even if there is a federal program it is still hard to implement it adequately. As a result, until very recently women did not have access to accurate information, nor the necessary tools to decide when to have children, and poor women were thereby placed in an ever more difficult situation.

“Assisted Reproduction and Local Experience: Women and Context in Latin America” analyzes the subtle influence of the Latin American context in assisted reproductive technologies. It considers the impact of technological advancements in developing countries, and the inadequacies of implementing the solutions of industrialized countries.

The main issues are, once again, the lack of respect for reproductive rights (the lack of sexual education and contraception, the failure to prevent sexually transmitted diseases, the prohibition of safe abortions), the status of embryos in the culture, and the promotion of a double standard. Context cannot be ignored. It fosters, in this case, secondary infertility. This fact should shape healthcare provision by promoting an all-embracing strategy that should prevent, as well as solve, infertility problems.

The remaining chapters focus on some of the ethical problems in research. “Social Science Research and Respect for Persons” takes the specific situation in social science research, where the question of obtaining informed consent or providing the research subject with information still meets with resistance. The chapter builds on some of the problems about intolerance and authoritarianism in medical practice mentioned above, and it was prompted by the publication of a book on ethics and research with Ruth Macklin. In that book, researchers in the field of reproductive health present and comment on cases and difficulties they have faced in countries like Mexico, Brazil, Chile, and Argentina. One of the recurring points is the lack of respect for research subjects. This was shown by the researchers hiding relevant information from the research subjects, failing to request their informed consent, taking their case history without consent, or intruding into their homes. I argue that these actions are incorrect. I speculate on the possible reasons for this behavior, and finally illustrate my point via an analogy with the history of abuse in biomedical research. Even if the kind of harm that biomedical research can inflict differs greatly from that of the social sciences, it does not minimize the harm that some researchers in this field can generate (especially when the research is related to stigmatized diseases and to reproductive issues that may be painful and cause anguish, like abortion or infertility).

Chapter Eight, “AIDS, Research, and Acceptable Codes,” focuses on AIDS and research. It examines the impact the AIDS pandemic has had on research. The impact began in the 1980s, when the carrying out of research and therapy were questioned, along with Food and Drug Administration (FDA) policies on the regulation and marketing of new drugs. The chapter goes on to examine the criticisms that arose in the late 1990s, and in the early years of the
twenty-first century, analyzing arguments and proposals for changes in laws and international research documents.

The second part of the chapter was initially written while the international research codes were being debated: the Declaration of Helsinki⁹ (modified in late 2000) and the guidelines of the Council for International Organizations of Medical Sciences (CIOMS)¹⁰ were being elaborated. However, the situation has moved on since then, and accordingly the 2002 version of the CIOMS Guidelines is considered as well as the debates that followed the Declaration of Helsinki.

The revision of Codes and Ethical Guidelines is necessary due to the unprecedented developments in science and the emergence of new problems, such as genetic research in general and in specific populations, data banks, the development of the AIDS vaccine, and the use of stem cell technology. However, in early 1999, a draft of the Declaration of Helsinki was presented on the Internet and discussed by the Council of the World Health Organization in Chile. It proposed, among other changes, a double standard for the protection and care of patients: one to be used in industrialized wealthy countries, and another to be used in developing countries. I analyze the justification, the impact, and the consequences that the draft’s proposals might have on people in developing countries. In the end, the suggested alterations were not incorporated. However—given the strong defenders such a position still has—it is worth considering how these changes might have an impact on countries in the South, many of which have a long tradition of research abuse.

Chapter Nine, “Ongoing Controversies,” considers two main sources of changes after the approval of the Declaration of Helsinki in 2000. It examines the debate on post-trial obligations and some of the arguments justifying the use of placebos in research in developing countries such as Uganda, Gambia, and Thailand, when a proven and effective therapy already exists. The chapter then reviews scientific, economic, and socio-cultural arguments, and cases are placed in a broader context that questions their justification. Variables that have not been satisfactorily considered are examined. Even if a knockdown argument cannot be given against making placebo use more flexible, an attempt is made to reveal the errors in the arguments for it, and to point out the elements that usually go unconsidered and that can skew an evaluation.

The final chapter, “Corruption,” examines matters that are “marginally” related to research. It treats a theme that has gone practically ignored in the field of bioethics—the possibility of corruption in work settings and the existence of systemic corruption in some countries. It approaches the possible incidence of corruption in the field of research. It explores the implications of the existence of diverse levels of corruption in various countries according to empirical work on an international level, and calls for an awareness of the implications these different levels of corruption can have for the design of international research.
These pages review the difficulties inherent in some developing countries (among them, the lack of respect for persons or intolerance), as well as external problems that threaten them (for example, diminished protection of already vulnerable populations). In an increasingly globalized society, let us remember that perspectives can differ, depending on whether you look at the world from the North or from the South.

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