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Bioethics in Canada

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FIRST EDITION

Charles Weijer, Anthony Skelton and Samantha Brennan

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Preface

We offer this anthology to those teaching bioethics in colleges and universities who seek to relate its core issues to the public policy context in Canada. In this volume, we have made a conscious effort to include articles from colleagues whose work we greatly respect but, for whatever reason, have not been included in prior bioethics anthologies. We hope the reader will, as a result, better appreciate the rich reservoir of talent present among those working in bioethics in Canada and Canadian bioethicists working abroad. In addition, we have intentionally aimed to educate the reader about the policies and laws that regulate the most important and pressing bioethical problems facing Canadians. We hope that the reader will develop a nuanced view of the nature, importance, and impact of bioethics in Canada.

This project would not have been possible without the invaluable assistance and hard work of a number of people. Jennifer Epp, Jason Marsh, and Angela ~~While~~ A. doctoral students at the Rotman Institute of Philosophy, expertly edited all of the articles in the volume. Rob Read, administrative assistant at the Rotman Institute, coordinated our meetings, scanned the articles, and supervised the copyediting process. The editorial team at Oxford University Press, including Stephen Kotowych and Meagan Carlsson, supported us throughout the creation of the book. We owe you all a debt of gratitude.

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Finally, we invite readers of this anthology to send us suggestions for topics and articles to be included in future editions. These can be sent to Charles Weijer (cweijer@uwo.ca).

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Introduction

This is a textbook in bioethics. Bioethics is an area of moral philosophy focusing on ethical problems in the medical and life sciences, including genetics and biology. The purpose of this book is to familiarize students with the most pressing problems in contemporary bioethics. It therefore focuses on such issues as the morality of using human embryos, adults and non-human animals in medical research; the morality of abortion and procreation; the morality of assisted suicide and euthanasia; justice in health care; the nature of informed consent, competency, disease and death; and the ethical issues associated with the cosmetic use of pharmaceuticals and the promotion of public health, among others. To situate ourselves, it is useful to begin with an actual bioethical case that raises difficult and not uncommon moral problems. This is the case of Baby Joseph.

Joseph Maraachli was born on 22 January 2010 in Windsor, Ontario. At birth, he appeared to be a healthy and normal infant. However, later that same year, on 31 May, he had a seizure and was admitted to a hospital in Windsor. He was later transferred to a hospital in Detroit, where it was discovered that he had neurological problems. Some months later, on 17 October, he stopped breathing while driving with his parents, and he ended up in a hospital in Ingersoll, Ontario. He was subsequently moved to the London Health Sciences Centre, in London, Ontario, and was placed on a ventilator. Physicians at the LHSC determined that he had a severe and progressive neurological disorder called Leigh's disease. It was possible for his seizures to be controlled, but no effective treatment for the disorder existed. Indeed, in the form that Baby Joseph had it, the disease is always fatal. While in hospital, Baby Joseph's condition deteriorated. He was unable to feed himself and to breathe spontaneously, and several attempts to remove him from the ventilator failed. Physicians later concluded that he had lapsed into a persistent vegetative state, and that it would be best to disconnect him from life support and to let him die. Baby Joseph's parents rejected this option, and instead asked the physicians to perform a tracheotomy on him, which is required for those needing a breathing machine permanently in place. This would allow his parents to care for him at home. However, the doctors refused on the grounds that keeping Baby Joseph alive would be "futile and cruel."

This response must have come as a shock to Baby Joseph's parents, since this was not the first time that they had encountered a scenario of this sort. Eight years earlier, Baby Joseph's sister Zina was born, and like Joseph, developed Leigh's disease, which is an inherited condition. Like her brother, Zina suffered from seizures, and eventually lost the ability to feed and to breathe without the aid of a machine. As in the case of Baby Joseph, rather than have her remain in hospital, Zina's parents requested that doctors perform a tracheotomy on her so that they could care for her at home. Unlike in the case of Baby Joseph the doctors complied with the request. She died ~~at home~~ a few months later at the age of 18 months.

The disagreement over the proper course of treatment for Baby Joseph led the eight physicians in charge of his care to conclude that his parents were no longer capable of making decisions in his best interests. They appealed to the Consent and Capacity Board of Ontario, a body that deals with conflicts of this variety, and the Board concurred with Baby Joseph's physicians. In essence, the Consent and Capacity Board argued that the physicians had the balance of reasons in their favour: Baby Joseph had "suffered enough human indignities" and it was reasonable to expect that a tracheotomy would lead to "exacerbated difficulties." It would be better, all things considered, for Baby Joseph to be taken off life support: keeping him alive had an unfavourable cost/benefit ratio. The parents appealed this decision, but it was upheld by the Ontario Superior Court of Justice on 17 February 2011.

The case did not end here. Several weeks after the court ruling, an American-based right-to-life organization calling itself Priests for Life intervened on behalf of the parents. Although many American hospitals refused to take Baby Joseph, with the help of Priests for Life he was flown to Cardinal Glennon Children's Medical Centre in St. Louis, Missouri, on 13 March. Some days later, physicians at the hospital performed the desired procedure. This allowed Baby Joseph to breathe with a portable breathing machine, and his parents returned home to Windsor on 21 April. Although he regained the ability to breathe on

his own and his condition seemed to be improving, he died slightly more than six months later, on 27 September 2011.

How do we determine the right course of action in this situation? How do we decide which party in this dispute has the most compelling moral reasons? Was the course of action recommended by the LHSC and supported by other institutions and medical experts wrong? Or was it impermissible for Baby Joseph's parents to put their son through a set of medical procedures appearing to have no benefit to him? Which factors matter to the morality of these decisions and courses of action? Which factors appear to be the most morally salient? The different parties in this case need to make decisions. What resources, moral and otherwise, ought they to draw on?

In order for us to begin answering these questions we must view moral debate as a practice that is governed at least in part by reason. That is, we have to agree that morality is something about which we can argue. Whether this is so, is a matter of long-standing philosophical debate. The best way to deal with it is by noting how difficult it is to avoid presupposing that some moral decisions are better justified than others. Indeed, as we see in the case of Baby Joseph no one suggested that anything goes with respect to his medical or other treatment. No one threw up their hands and declared that it was all a matter of opinion or emotion, and that there was no truth about what ought to be done. Instead, what we find is each party in the conflict attempting to provide reasons and trying to identify factors that they think matter morally. That is, we find that each party in the dispute is trying to move the other by rational means. This should come as no surprise to us, for we have a conception of ourselves according to which our intentional acts are not the product of arbitrary and random forces. On the contrary, we think of our intentional actions as being justified or as being backed up by reasons that others at least recognize or might be in a position to accept. These at least in part are what move us to act. We simply cannot accept that anything goes or that what we do is permissible only because we think or want it to be so. Otherwise, why would we agonize over the issues and problems that we do?

But what does moral reasoning look like? What counts as a moral reason? Answers to these questions are also a matter of long-standing philosophical debate. It is important for our purposes to avoid controversy and, more significantly, to avoid assuming what readers of this anthology will decide for themselves about what matters morally. However, it is important to note that moral reasons are distinct from legal reasons, on the one hand, and religious reasons, on the other. Though these can and often do overlap, the three kinds of reasons remain distinct. A legal reason is one that is typically found in a statute or a legal precedent; a religious reason typically derives from a religious text of some kind (e.g., the Koran). Some of these reasons are moral reasons, too, but not necessarily. It is of course difficult to say what makes a reason a moral reason, but typically moral reasons have to do with human rights, well-being, justice, virtue, fidelity to promises, dignity, and respect for individual autonomy. In addition, moral reasons are not codified in the way that legal and religious reasons are. Finally, moral reasons typically have a much broader reach than either legal or religious reasons. Indeed, we rely on moral considerations to assess and sometimes criticize law and religion. These are factors that seem to matter regardless of what law and religion dictate.

With these considerations in mind, we may be able to make sense of what bioethical or moral reasoning would look like in the case of Baby Joseph. To begin, it is important that moral disputants agree on the facts. Sometimes moral disagreements are the result of factual disagreements, such that once the factual disagreements are cleared up the moral disagreements evaporate or become more tractable. The disagreement between Baby Joseph's physicians and his parents appeared to turn on disagreements about his medical status. One physician commenting on the case stated that withdrawing a feeding tube would not necessarily be painful but that a tracheotomy might be, and that you have to weigh this cost against any benefit to Baby Joseph. But Baby Joseph's parents were sceptical of the claim that a tracheotomy would be painful. He appeared to possess a level of consciousness that was inconsistent with him feeling anything at all. In addition, the parents disputed the claim that Baby Joseph was in a persistent vegetative state. According to the Priests for Life website, Baby Joseph was instead in a near-vegetative state (http://www.priestsforlife.org/articles/3620-baby-joseph-is-home-and-breathing-free). It is possible that had these facts been agreed to by the physicians in charge of Baby's Joseph's care that they would have

performed a tracheotomy as physicians had in the case of Baby Joseph's sister.

However, there is reason to think that the factual disagreements are of only minor significance in this case. Instead, there appear to be deep moral disagreements between Baby Joseph's parents and his physicians. In a newspaper article, Baby Joseph's father, Moe Maraachli, is reported to have said "Let me take him home and let him breathe . . . If he will die, he will die because he's sick, naturally." The reason that Mr. Maraachli wanted to take his son home had less to do with his attitudes about his son's condition and more to do with his attitudes regarding the best way for him to die. Mr. Maraachli seemed to think that it would be worse for Baby Joseph to die from not breathing, which would have happened had his breathing tube been removed in the hospital, than from the underlying disease from which he was suffering. This was further confirmed by the fact that upon Baby Joseph's death a spokesperson for the family, Paul O'Donnell, is reported to have said that "What they [Baby Joseph's parents] wanted was to let their baby die peacefully and naturally when God decides and not have that imposed by the hospital or the courts."

~~Baby Joseph's parents also disagreed with his physicians over how to answer the following question: What factors should count in favour of continuing Baby Joseph's life?~~ It was assumed by all that ~~his~~ interests were of importance. But his parents also considered another factor in their decision-making~~:~~ they wanted more time with Joseph. This was, to them, a benefit to be weighed against the cost of the treatment. In a newspaper article, it was reported that Baby Joseph's parents enjoyed the extra time they had with Zina and that they wanted to have the same experience with Joseph. It seemed that the parents were including a benefit that the physicians had simply ignored, the benefit to Baby Joseph's parents of having him at home and of caring for him until he died. This benefit to the parents may well have been thought to outweigh the risks that the surgery posed to their son.

The reasons in favour of respecting the choices of Baby Joseph's parents are very strong. They seemed to be relying in part on their core and deeply held religious convictions (Mr. Maraachli is a Muslim, while Baby Joseph's mother, Sana Nader, is a Catholic). Furthermore, the parents had a more detailed and nuanced knowledge of their child and of caring for children of this sort, and they were more than willing to assume the bulk of Baby Joseph's care (though a nurse looked after him from midnight to 0700h while he was at home). Finally, there is a strong presumption in the common law and in ethical thinking that medical decisions of the sort at issue in this case are the sole responsibility of the parents.

The family's decisions and the reasons that speak in favour of them seem to be of the utmost importance in cases like this. Nonetheless, it is important to consider the other moral factors that matter. The health care team that was responsible for the care of Baby Joseph had equally strong reasons for the decision that they made. They are experts in the care of infants suffering from the condition that afflicted Baby Joseph, and they deal with these cases on a routine basis. The decision that they made in this case concurred with the decisions that other experts typically make in similar situations; and in some jurisdictions decisions of this sort are mandated by law irrespective of the parent's wishes. The health care workers have a duty to care for the infant to the best of their ability and to do so with only the infant's best interests in mind. Most important of all, they have a duty not to perform surgery that is unlikely to produce a benefit for the patient. A less compelling reason, but no less worthy of note, is that physicians have to think of the opportunity costs of sustaining lives like Baby Joseph's. If the physicians believed that there was no benefit to keeping Baby Joseph alive, then it would be unfair to others who might benefit from such care for the physicians to continue to care for him.

Aside from the two parties immediately involved in the situation, it is important to consider two further groups: the administrators of LHSC, and society at large. The administrators of LHSC have to manage the care of a plurality of patients in a way that is efficient and designed to produce the most desirable outcomes for all. In order to do this they have to adopt general principles or best practices to guide their choices. This involves not only thinking about what certain principles imply for particular cases, but what these principles imply for all cases of the same nature. The administrators must decide how to handle cases like these and must avoid permitting exceptions that might set undesirable precedents. Finally, they have to decide issues on the basis

of sound scientific evidence, rather than expediency, which would imperil the medical and scientific integrity of their institution.

The second group that it is important to consider is the community in general. The decisions that Baby Joseph's doctors made are not isolated decisions. They take place within a society, and it is important to understand the general effects of permitting people to act in certain kinds of ways. On the one hand, one might plausibly worry that licensing physicians to act in ways that were suggested by Baby Joseph's own physicians might have a corrosive effect on how well patients like Baby Joseph are treated. On the other hand, one might worry that permitting parents to make the ultimate choice as to the sorts of medical procedures their children undergo may undermine the legitimate authority of medical and similar practitioners and result in problematic outcomes for vulnerable children and for the care of other patients.

The solution to this case involves thinking about all of the reasons enumerated above. It is determined in particular by how you weigh the various reasons against each other. This is aided by judgement, reflection, sympathy, and a keen understanding of the case's context and the particular and general outcomes of decisions about it. This is therefore a case that defies easy resolution. Most important of all, the case of Baby Joseph is not atypical. It is the sort of case that is the stock and trade of people working in bioethics and related fields. This book examines the issues raised by cases like this by relying on arguments, theories, and concepts developed by philosophers working in moral theory and political philosophy. However, the presupposition of this book is that it is a mistake to think that we can deal with these issues simply by applying a normative moral or political framework directly to them. Instead, we think that such theories are often too poorly defined and the issues too complex for this to be an option. The complexity of the case of Baby Joseph seems, quite clearly, to demonstrate this fact. It is far from obvious what the standard theories imply for this case. Our view is that it is much more productive to explore bioethical issues directly, to determine their ethical dimensions and their social complexity, and only then to rely on theories to help with the process of ethical decision making. This set of claims runs contrary to the common idea that bioethics is simply just one part of what is often called "applied ethics," which, roughly speaking, involves the top-down and sometimes mechanical application of a moral or political theory to practical moral issues. The idea in applied ethics is that one assumes a particular moral outlook, which one then applies to some practical problem and from which one receives a practical directive. Our orientation is that this is an impoverished view of ethics, one that is particularly ill-suited to bioethical reasoning.

Our view of the role of moral and political theory in bioethical reasoning is reflected in the organization of this book. This volume begins and ends with chapters focusing exclusively on problems in bioethics. Its core focus—in its first 12 chapters—is the most urgent bioethical problems arising between the conception and the death of the typical human being. It does not begin with a chapter in which various moral theories are outlined and explained in isolation from the problems that they help to deal with. Instead, this book is designed so that certain theoretical orientations emerge in each of the readings as part of the natural course of reasoning about what we ought to do with respect to the specific bioethical problem under consideration. We believe that this is a pedagogically more valuable way to assess the role and importance of moral theory to bioethical reasoning. It is of little value to students of bioethics to discuss theories in complete isolation from bioethical problems. The main problem that we see with the "free floating" discussion of ethical theories is that it does not do justice to the ways in which theories actually relate to practical ethical problems and are altered and modified in light of these problems. It is of little value to explain Kantianism or utilitarianism in the abstract and then to turn, for example, to the morality of medical research using adults. It is better in our view to first begin with the issues raised by such research and only then to discuss how a particular theory might deal with the issue in this context.

In addition, the thematic focus of this book's core chapters reflects the fact that bioethics is not, in our view, primarily focused on the moral problems that arise in the treatment of the autonomous human adult and only secondarily on those who fall outside this category, e.g., human embryos and children. The book's core chapters deal instead with each segment in the typical human life span and the moral problems that are germane to it. It does not treat these segments as mere deviations from the norm of the autonomous adult. Our approach to bioethical

problems has the advantage of beginning with a question that is important to any ethical discussion, namely, who has moral standing? We begin by examining whether human embryos and fetuses deserve direct consideration. We stop, in chapter three, to deal with the issue of what sort of child a parent should want to produce and what sort of care they are required to provide. We then move to the issue of how we treat those with full moral standing in a variety of contexts, including medical treatment, research, the health system, and end of life care. This involves discussions of justice, both national and international, and many important conceptual issues, e.g., the definition of death, informed consent, competency, equipoise, and so on.

We believe that this book possesses a number of helpful features. First, it focuses for the most part on Canadian bioethical cases and bioethical issues raised in Canadian public policy and law. In addition, it features a substantial number of Canada's leading philosophers working in bioethics. This is therefore a book for those studying in Canada and wanting to learn about what Canada's leading minds in bioethics have to say about its most pressing problems. Second, the book includes a variety of useful tools for students. Each of the seventeen chapters comprises the following features: a set of readings designed to reflect a plurality of approaches to a single moral issue, all of which have been edited for length to better reveal its argumentative structure; a set of study questions at the conclusion of each reading, which help to focus the reader; a set of study questions at the conclusion of each chapter, which focus on the similarities and differences between the chapter's readings; a passage from one of the readings for critical analysis, which is designed to help students hone skills of analysis and criticism; a case study that is realistic and relevant to Canadian society, i.e., which deals with Canadian practices and policies; and finally, ~~each chapter contains~~ suggestions for further reading, including many online sources, for use by instructors and students looking to examine an issue more thoroughly.

There are of course many ways an instructor might use this book. Our main aim has been to provide instructors with a self-contained introductory course in bioethics lasting twelve or thirteen weeks. The book is not designed to give instructors many options within a chapter; each chapter's articles are meant to provide both diverse and often competing approaches to a problem. Time may not allow an instructor to discuss all three of the articles in each chapter. In this case, it should be noted that the first two articles in each chapter are considered its core articles, while the last is considered supplementary. We envision instructors relying heavily on the chapters in the core section of this book, chapters 1 to 12, since these chapters survey the most divisive and compelling issues in contemporary bioethics. However, some of these could be replaced or supplemented by the non-core chapters, 13 to 17. These chapters cover a range of issues, including the nature of disease, ethical issues associated with the promotion of public health, the morality of using non-human animals in research, neuroenhancement, and sexual justice and health care. The following Content Correlation Grid might be of use to instructors who choose to use this book in a way other than what is suggested by its explicit editorial design. Highlighting various themes, the grid should act as a guide when coordinating your course with the text. These are just some of the possibilities and our hope is that this book will be of use to even the most imaginative instructor.

Content Correlation Guide

	Moral Standing	Health And Justice	Ethics of Killing	Reproductive Ethics	Research Ethics	Bioethics and Autonomy	Feminism and Bioethics	Bioethics and the Marginalized
CHAPTER 1: Conception and Embryos	✗		✗	✗	✗		✗	
CHAPTER 2: Fetuses	✗		✗	✗			✗	
CHAPTER 3: Procreation and Child rearing				✗			✗	✗
CHAPTER 4: Adults and Decision-making						✗		
CHAPTER 5: Conflict about Appropriate Treatment						✗		
CHAPTER 6: Equipoise and Clinical Research		✗			✗	✗		
CHAPTER 7: Justice and Access to Health Care		✗						
CHAPTER 8: Obligations to the Global Poor		✗						✗
CHAPTER 9: Assisted Suicide and Euthanasia			✗			✗	✗	
CHAPTER 10: Defining Death	✗							
CHAPTER 11: Harvesting Organs from the Dead						✗		
CHAPTER 12: Bioethics in a Pluralistic Society		✗					✗	

CHAPTER 13: What is Disease?								✗
CHAPTER 14: Public Health		✗				✗		
CHAPTER 15: Research on Non-human Animals	✗		✗		✗			
CHAPTER 16: Neuroenhancement						✗		
CHAPTER 17: ~~Sexual~~ Justice and Health Care		✗					✗	✗