Care and Respect in Bioethics

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By

Darlei Dall'Agnol

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To Juliana:
with care + respect = love.

While the ethics of rights is a manifestation of equal respect, balancing the claims of other and self, the ethics of responsibility rests on an understanding that gives rise to compassion and care. Thus, the counterpoint of identity and intimacy that marks the time between childhood and adulthood is articulated through two moralities whose complementarity is the discovery of maturity.
—Gilligan

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ACKNOWLEDGMENTS

This book presents the results of my work in bioethics over the past eight years. The idea was born in May 2007 when I read the paper "Care & Respect in Medicine" at the faculty seminar "Bioethics, Values & Society" in the Medical School of the Health System at the University of Michigan, US. I was in Ann Arbor doing post doctorate research under Professor Stephen Darwall's supervision, and I wanted to develop the project of a new moral epistemology, namely practical cognitivism, which will become apparent here. The suggestions and criticism of Susan Goold, Mike Fellters, Maria Silveira and David Shalowitz led me to plan an extended work. This is it.

At that time, I was focusing mainly on meta-ethical issues, but I then came across Darwall's theory of rational care, which I will reconstruct later, and started to ponder its implications for bioethics, especially whether it was able to avoid some forms of paternalism, a topic I discussed with Darwall several times. Thus, I got the idea of 'respectful care' through conversations with Darwall, and I am in debt to him for much of the inspiration for this work. I would also like to thank Peter Railton for our discussions in Ann Arbor and in Florianópolis, especially for his encouragement to develop a new moral epistemology based on the idea of *knowing-how* to ground respectful care.

In 2009, I spent four months at Michigan State University, in East Lansing, a well-known place for bioethical studies mainly from a feminist point of view. There I read the paper "Care & Respect" (now published in *Bioethikos*) in a joined section of the Center for Ethics and Humanities in the Life Sciences and the Department of Philosophy, and the contributions of the audience, especially those of Hilde Lindemann and Jamie Nelson, were important in expanding the work to include care ethics. I will discuss some of their ideas throughout this book. In East Lansing, I completed a first draft of this book, and I am grateful to Professor Frederick Rauscher for our philosophical conversations during this time and afterwards, especially on the extent and limits of the Kantian principle of respect for persons.

Back in Brazil, I continued thinking about the meta-ethical and normative bases of bioethics, but my teaching duties and my role as the

Director of the Graduate Programme in Philosophy at the Federal University of Santa Catarina forced me to put the book to one side for a while. Despite this administrative function, I had the opportunity to discuss some parts of this work with Brazilian colleagues at many conferences. Thus, I would especially like to thank Dr. Marco Azevedo for his critical comments on the first draft. Thanks also to the graduate students who contributed to my work; I will not mention names here since I fear leaving many out. I would also like to thank the editors of *Bioethikos* for authorizing the publication of parts of my paper "Cuidar & Respeitar: atitudes fundamentais na bioética," in which I first presented the idea of respectful care in print.

In 2012, I went to Georgetown University for the 38th IBC – Intensive Bioethics Course. I felt that I had to learn the basics of the predominant bioethical theory in Washington. Thus, I would like to thank Carol Taylor and Maggie Little for our discussions on the normative foundations of bioethics. I owe to Carol an interesting and updated reading of the so-called "principlism" or "the four principles approach" (*respect for autonomy*, *non-maleficence*, *beneficence* and *justice*), the Georgetown Mantra. I would also like to thank Maggie Little for her important input on the epistemology to ground respectful care. I will discuss Little's particularist interpretation of Wittgenstein's ethics as well as casuistry and other relativistic views throughout this work. The discussion of the meta-ethical and normative bases of bioethics is here centred around principlism. Basically, I criticise the intuitionist meta-ethics of principlism substituting it for practical cognitivism in proposing a new bioethical concept, namely respectful care. I got this idea during the 38th IBC.

In its final form, this book is the result of a sabbatical year and my research carried out as a Visiting Scholar at the Uehiro Centre for Practical Ethics, at the University of Oxford, UK, in 2015. Thus, I would like to thank especially Professor Roger Crisp for supervising my work, Dominic Wilkinson for our conversations on the normative foundations of neonatal bioethics and Julian Savulescu for his constant support. The idea of respectful care was published in English on Uehiro's blog *Practical Ethics in the News* together with associated posts such as "caring robots", "caring for our home" and "enhancing wisdom" (see: http://blog.practicalethics.ox.ac.uk/darlei-dallagnolls-posts/), which are parts of chapters of this book. I would like to thank the Uehiro Centre for authorizing the use of this material. I would also like to thank the *Journal of Medical Ethics* (v.42) for authorizing the publication of an extended version of my essay "Knowing-how to care," which is now part of this work (chapter 5), that is, the bulk of this book.

I benefitted also in writing the final version from some suggestions made by Frederick Rauscher and Roger Crisp. I could not, however, respond to all their comments and I apologise in advance for the remaining mistakes. I would finally like to thank Kim Butson for helping revise the grammar. Last, but not least, thanks to CAPES and CNPq, two Brazilian federal agencies, for providing financial support for my research over the years.

INTRODUCTION

This is a work on the *philosophical* foundations of bioethics. The main problem it deals with is related to the tensions and potential dilemmas generated by the intuitionist meta-ethical commitments of the predominant normative theory, namely “the four principles approach” (also known as “principlism”). This view is based on the *prima facie* norms of respect for autonomy (*one ought to respect the autonomous choices of subjects of scientific research/patients*), non-maleficence (*one ought to refrain from inflicting harm*), beneficence (*one ought to do good and prevent or remove harm*) and justice (*one ought to treat people fairly*). I will examine this approach in greater detail in chapter 3. The tensions in applying these basic principles may lead to inaction in scientific experiments involving human subjects or to arbitrary applications of the norms in the art of caring. My main goal is then to find a proper balance between caring & respecting at the normative foundations of bioethics. The problem can be made explicit in these terms: on the one hand, caring without respecting seems blind, degenerating into forms of paternalism when, for instance, the one-caring imposes her conception of the good life or a particular procedure on the cared-for; on the other hand, respecting without caring amounts to indifference or individualism when, for example, a person does not look after a vulnerable being properly. The question then is: how can we avoid both paternalism and indifference in caring & respecting?

My initial hypothesis is that the concept of *respectful care* can be built up, working from an ethico-philosophical perspective, to be a leading notion capable of guiding our daily actions and bioethical practices. This concept has the potential to overcome the problematic intuitionist meta-ethics of the predominant normative theory in bioethics. In order to show this, I will formulate a new moral epistemology, practical cognitivism, to give support to the concept of respectful care and, consequently, to provide better bases for bioethics. To recognize its plausibility, I will illustrate how it might work in *a* common, sharable morality, paying particular attention to bioethical cases in the neonatal context. I will then argue that a respectful caring manner may be considered one of the most fundamental *attitudes* we must cultivate in all domains of our moral lives. I will exemplify its implications particularly in the field of bioethics because this moral domain raises issues that concern us all, such as whether we should edit the human genome to avoid disabilities using CRISP-Cas9, whether abortion is morally permissible, whether we should be assisted in dying etc. Respectful care is not only undoubtedly important in scientific research involving human subjects, especially in the health care system, but also in all domains of our daily lives.

I will, methodologically speaking, use conceptual analysis as an important philosophical tool. That is to say, I will *search* for the conditions (I hope the necessary and sufficient ones) under which we apply correctly a word, an expression etc. as it was put forward, for instance, by Nel Noddings in her book *Caring* (p.69)*:* “logically, we have the following situation (W, X) is a caring relation if and only if:

i) W cares for X (as described in the one-caring) and
ii) X recognizes that W cares for X.”

Noddings’ analysis does not seem right to me as some conditions are not necessary at all (e.g., the cared for does not need to recognize that the one caring is looking after her), and even if they were, they would conjointly not be sufficient. Moreover, her analysis seems circular: she cannot use the *analysans* “cares for” to clarify the *analysandum* “caring relation”. Thus, I will look for a better one, without pretending to offer a final analysis, especially in terms of a *respectful* caring attitude and apply it using concrete, practical bioethical cases. My analysis of knowing-how to care respectfully will try to overcome the difficulties generated by the intuitionist meta-ethics of principlism. In this sense, the general aim of this book is to rethink the meta-ethical and normative bases of bioethics in order to offer a better alternative to the predominant approach.

In order to achieve this general goal, I will, in the first chapter, reconstruct the main tensions and apparent dilemmas between caring & respecting (section 1.1) in the domain of what can be called “special bioethics”, that is, the ethical problems involved in doing research using human subjects in, especially but not restricted to, the biomedical sciences. To illustrate such problems, I will tell the story of Baby 1 showing why the predominant bioethical approach apparently fails to give a proper solution to the ethical problems of the case. I will then, in section 1.2, discuss the need for both a new concept in special bioethics to avoid the problems and an innovative moral epistemology to ground it, two tasks a solid *philosophical bioethics* must be capable of accomplishing.

In the second chapter, I will start to scrutinize some of the meta-ethical commitments of the predominant approach beginning with the supposed consensus reached around the Belmont Report (US, 1978), when bioethicists of different ethical traditions, namely casuists, utilitarians, deontologists, etc. reached a "compromise" on basic principles for research involving human beings. This report gave rise to principlism. Thus, in section 2.1, I will discuss methodological questions such as whether we should work with cases only, as the commissioner and philosopher Albert Jonsen argued in cooperation with Stephen Toulmin; or with universal principles too, as the principlists Tom Beauchamp and James Childress held later. I will, in section 2.2, make a detailed reconstruction of the three basic principles of the Belmont document, namely *respect for persons*, *beneficence* and *justice*.

In the last forty years of bioethical discussions, there have been two main departures from the Belmont framework, which I will examine in the third chapter. First, in their now classic book *Principles of Biomedical Ethics*, Beauchamp and Childress argued that we should work with *four* principles instead, dismembering non-maleficence from beneficence, and that a basic norm is respect for *autonomy* and not respect for *persons*. They kept, however, the intuitionist meta-ethics of the document. I will discuss their principlist views, which became predominant, in section 3.1. Second, both Tristam Engelhardt and Edmund Pellegrino have tried to overcome the problems generated by the four principles approach by ranking *one* basic norm over the others and, in this way, abandoning the intuitionist meta-ethics. Thus, I will, in section 3.2, discuss these solutions, which lead to *autonomism* and *the beneficence-in-trust model*. To point out the problems of these approaches, I will introduce the case of Baby 2 arguing that we should look for a better way of integrating care & respect into a coherent whole leading to the idea of respectful care as the core concept for *a* common, sharable morality.

In the fourth chapter, I will scrutinize the idea of *the* common morality used by the principlists to ground bioethical decisions. I will, in section 4.1, make a reduction of the principles of respect for autonomy and justice re-analysing the idea of *respect* for a person's rights. Moreover, I will reduce the principles of non-maleficence and beneficence to *care* also re-analysing this concept in order to point out a way of integrating care & respect into the concept of respectful care. As we will see, these are the main cornerstones of *a* common, sharable morality. To illustrate how this might work, I will, in section 4.2, discuss end-of-life care, especially whether we should kill or let die premature babies with no prospect of cure. As we will see, taking a life can paradoxically be seen as an expression of compassionate care. That is to say, we must *know-how* to care in a proper way.

In the fifth chapter, I will then present the main tenets of a new moral epistemology, namely practical cognitivism, to give support to the idea of respectful care. I will do this mainly in section 5.1. In order to achieve this goal, I will introduce the case of Baby 3 showing what care without respect amounts to. In the second part (5.2), I will finally propose a conceptual analysis of knowing-how to care respectfully sorting out the necessary and, I hope, sufficient conditions to apply this fundamental bioethical notion. This will, I believe, be the main contribution of this book.

In the next chapter, I will go back to the cases of Baby 1, Baby 2 and Baby 3 considering what would have been the right course of action had the concept of respectful care been taken seriously. These bioethical cases are just illustrations of how respectful care might work. They will be discussed in section 6.1. Moreover, I will, in section 6.2, argue that one of the central roles of bioethics committees is to guarantee that respectful care is always in place in our daily acts and bioethical practices.

Finally, I will consider how respectful care may be extended to other bioethical domains, especially to what can be called “global bioethics” (the discussion of bioethical issues in the international arena) and “holistic bioethics”, that is, caring for life as a whole including the environment and non-human animals. As an illustration, and to keep an eye on the future, I will speculate what a respectful caring robot may look like in section 7.1. Some bioethical issues related to the original idea of bioethics as a concern for life as a whole will be discussed in section 7.2. The integration of “special bioethics” with “global bioethics” and “holistic bioethics” is realised by the idea of a *philosophical* bioethics.

The justification for this work can be put in very simple terms: bioethics deals with questions of life and death that concern us all, so it is crucial to get its meta-ethical and normative foundations right. To know-how we must live (and die) is no trivial issue. In fact, I know of no more important matter.

CHAPTER ONE

CARE *VERSUS* RESPECT

To start with, I would like to sort out in greater detail the background *problem* I am trying to present a solution to here. Caring for and respecting someone are, according to some current (bio)ethicists, two ways of intrinsically valuing an individual and/or a person. For this reason, they are frequently considered fundamental moral and bioethical notions, and it seems natural to assume that they would form a harmonic whole guiding our moral lives, our everyday actions such as looking after our children or caring for non-human animals and also most of our complex practices, for instance, doing biomedical research and scientific experimentation on vulnerable patients. In other words, they appear to complement each other. Common sense or sound judgment seems to tell us that this is really the case. However, these moral notions may also clash with each other and even stand in opposition generating tensions, conflicts and dilemmas, which may ultimately lead to inaction. Most forms of paternalism, that is, the intentional overriding of a person's preferences and values with the goal of supposedly benefiting her, are disrespectful.

These tensions are sometimes cast in the following languages:

i) attempts to foster collective wellbeing or the welfare of a given community *versus* accepting individual preferences;
ii) the long Hippocratic tradition in medicine requiring us first *to care for* the patient *versus* a modern morality that demands first *respect for* the patient's lifestyle, values and choices;
iii) the responsibilities of doctors and/or researchers in their dual roles as scientists and as physicians in biomedicine *versus* the rights of the subjects of scientific experimentation;
iv) a female moral voice supposedly based on personal commitments and sentiments *versus* a male morality allegedly based on impartial rights and principles of justice;
v) the particular requirements of contextualized caring *versus* universal values based on respect.

I will argue in this work that these tensions do not lead to *real* moral dilemmas or even to opposite moralities and that most conflicts can be resolved.

These tensions are not bad in themselves (as they are not in music, in love or in many other domains of human life) and may even perform a creative role, but they certainly call for a resolution. The dialectical contrast between opposites may generate harmony, but the tensions between caring & respecting can also lead to inaction if they are not solved or dissolved. It might be the case that care & respect stand for two opposite poles in our moral lives and that they limit each other creating a harmonic whole. That is to say, it seems to be the case that respect *limits* care, avoiding it turning into paternalism; and that a caring attitude complements respect, escaping indifference or individualism. Consequently, finding the right equilibrium between caring & respecting is nowadays one of the main challenges in philosophical ethics, and it constitutes the main ambition of the present work.

Some important bioethical questions then are these: is it really possible to reach a right balance between caring & respecting? How can we regard them as interconnected, as mutually supporting attitudes capable of overcoming the above mentioned dichotomies? Are they in fact incompatible and, for instance, respect for a patient's autonomy must always *trump* welfare concerns when they conflict? To give an illustration: what about a patient's request (or from her proxy/surrogate) for an *experimental* drug or some medical procedure that offers no clear benefit and may even cause potential harm, is a health professional under the obligation to provide it? If not, does that not constitute negligence or malpractice?

In this chapter, I will reconstruct in a more detailed way how caring & respecting may conflict and start to look for a resolution of these tensions. In the first section, I will present a particular case to illustrate how care may not always be accompanied by respect. In the second section, I will propose the idea of bioethics guided by philosophical *wisdom*, which can be defined in terms of knowing-how to live well, as a discipline capable of integrating caring & respecting into a coherent whole in our moral lives.

1.1 Caring and disrespecting

In order to illustrate at once the complex imbrications between caring & respecting, let me introduce a particular bioethical case involving, on the one hand, health professionals, researchers (some in fact with dual roles), students etc. and, on the other hand, a very special patient, an extremely-premature baby, who happened to be in a circumstance where she could also be the subject of experimental scientific research in a teaching hospital. Consider then the following real life case, reconstructed here in the Hastings Center Report's style, which does not imply that I am assuming a casuistic-based approach to bioethical problems:

> Baby 1 was born prematurely (23 weeks), on 07/15/2006, Michigan, US. She weighed 1 pound and 5 ounces and was 11 3/4 inches long. Baby 1 belonged to the Extremely Low Birth Weight (ELBW) group of babies. She had small haemorrhages in her brain and respiratory failure. On 08/04/2006, she was transferred to another NICU (Neonatal Intensive Care Unit) because she required surgical placement of a ventricular reservoir to relieve pressure on the brain caused by bleeding. Because of her immature lungs, she breathed with the aid of a ventilator and was receiving morphine to relieve pain. She had infections and was on antibiotics. On 09/01/2006, she was diagnosed with a potentially fatal intestinal disease, namely NEC (*Necrotizing Enterocolitis*) which causes bowel tissue to die. She could not survive and was expected to live 2 days more. The parents agreed that *palliative care* only was appropriate and prepared themselves for the worst. After 2 weeks, however, the baby was still alive and being kept comfortable with sugar water and potassium, but with no nutrition at this time (and surprisingly) *against* the wishes of the parents. A suit was filed on 09/15/2006 against the U. of A. (the hospital's fictional name here) naming the Regents, 4 physicians and other staff as defendants. The parents went to court arguing that only they had the right to decide whether life sustaining treatment should be given or withheld. Meanwhile, a second opinion was sought. Some hospitals were apparently willing to accept a transfer (e.g., Toledo Children's Hospital), but they made clear that they probably couldn't do better than the U. of A. Besides, the parents' health insurance would not cover the transfer. The Ethics Committee of the U. of A. decided, in any case, that Baby 1 should not be transferred. An intestine transplant was also considered (at Children's Hospital of Pittsburgh), but the responsible paediatric surgeon decided that no further treatment was appropriate since the arteries that normally supply blood to the intestines were clotted and useless. Just one night before the court hearings, which could have ordered the hospital to increase care, Baby 1 passed-away (09/19/2006).

These are some of the basic *facts* of the case; other facts and some ethical reflections will become apparent throughout this book. Note, however, that I am distinguishing scientific *facts* from *values*, which will be discussed below. We need to do that not only to provide a proper solution to the case, but also in order to avoid conflating scientific issues with ethical ones.

Take another look at the picture on the cover of this book. Preterm babies in these conditions are in a very fragile, extremely vulnerable state. This is perhaps the plainest example of the *vulnerability* of the human condition and of the unquestionable fact of *our mutual interdependence*. No doubt, Baby 1 needs attention, but *how* best to care for her? The blue plastic tube is the ventilator, attached to a computer that regulates the speed at which she breathes and the percentage of pure oxygen in each of those breaths. The round patch stuck to her chest is to measure her heartbeat. The needles in her arms provide medication and nutrition. The thin wires are threaded into an umbilical artery and vein to give intravenous fluids. The patches over her eyes protect from blindness etc. We are no doubt care-dependent creatures. A crucial ethical question is this: are we not *disrespecting* Baby 1?

There are other questions: should we use technology just because it is available even if it produces more harm than good, that is, should we follow the technological imperative ("what *can* be done, *must* be!")? Perhaps the central question is whether technicized medicine is not doing too much and thus causing more harm than good. So, when is enough really enough? Why should we not allow a baby in this condition to die in peace before starting any lifesaving support? Is euthanasia morally permissible? Why not euthanize Baby 1 instead of withdrawing food, just because the parents have strong religious values? But should doctors' decisions be bound by religious beliefs? Is there a background conflict between a scientific and a religious worldview in this case, if so, which should prevail?

The predominant normative theory in bioethics, namely the four principles approach, based on the *prima facie* norms of respect for autonomy, non-maleficence, beneficence and justice, which will be examined soon in greater detail (section 3.1), apparently fails to give a proper solution in this case. That is to say, it in no way tells us whether we should *respect* the parents' request to increase care or accept the doctors' prognosis that palliative *care* is the only course of action morally and technically recommended. It has no clear criterion to apply either the principle of respect for autonomy *or* the principle of beneficence. This is even recognized by the main proponents of principlism: "These conflicts sometimes produce irresolvable moral dilemmas."[1] Now, a moral dilemma is a situation where an agent is under two obligations, but it is impossible

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[1] Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, (New York/Oxford: Oxford University Press, 2013), 12.

to perform both duties. Moral dilemmas, however, may not be real.[2] Most likely, they are only *apparent* given the epistemic limitations of the agent. They cannot anyway be generated by the bioethical theory itself. This is unacceptable and shows that the predominant bioethical theory seems flawed. How did we come to such a state of affairs in bioethics, including in the neonatal context?

In order to answer this question, we need perhaps to understand better the development of this particular science, namely neonatology, and its *moral* challenges. It can generally be defined as the science of the diagnosis and treatment of disorders that affect newborns. Neonatology, which provides high-intensive care to premature infants, is one of the most technically sophisticated areas of medicine. It is fascinating, but it also deals with hard moral cases. It can be an aggressive, intrusive branch of medicine. Paediatricians may do everything within their power to keep, so to speak, this "patch of flesh alive." As the present story of Baby 1 shows, moral dilemmas concerning the choice between saving the patient or letting her die may be routine. New technologies have made it possible to save the lives of infants who only a few years ago would certainly have died. We can, for instance, recall here that the surfactant (for example, poractant alpha), which coats the tiny air sacs of the lungs, is a recent scientific discovery. This is a fine example of how science can work for our benefit, to increase our wellbeing. Without it, Baby 1 would not have survived the day she was born. There is little doubt then that the sciences and technology can be used for our own good. We need to ask, however, ethical questions as well: what about the consequences of the treatment, for instance, will the baby suffer from a severe intellectual disability or any other impairment later in life? Should we save her or let her die? There is no easy answer to this latter question. As can be seen, moral dilemmas are still very common in this medical area as the Baby 1 case clearly shows.

To find out what went wrong in Baby 1's case, we also need to present some developments in neonatal bioethics. That is to say, her story needs to be seen in the context of developing new treatments in neonatology and the *moral* challenges this brings. Now, according to Lantos and Meadow,

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[2] As Tristram Engeldhart wrote (*The Foundations of Bioethics,* New York/Oxford: Oxford University Press, 1996, 103): "This tension can be appreciated as the conflict between two ethical principles: that of permission and that of beneficence." Now, if one gives always absolute priority to permission, then the tensions disappear and there is no *real* dilemma. I will discuss Engelhardt's solution later.

the development of neonatology in the past decades has gone through three different eras:

i) *the era of innovation and individualism* (1965-1982). This era began with the introduction of mechanical ventilation for premature babies and was driven by the technological imperative, which meant that whatever could be done to save the babies' lives ought to be done;
ii) *the era of exposed ignorance* (1982-1992). This era began with a controversy over a case, namely Baby Doe, who was allowed to die rather than undergo lifesaving surgery. During this era the paediatricians and neonatologists began to face criticism for inappropriately withholding treatments that parents might have wanted. There was no consensus about what ought to be done in most cases, that is, doctors did not know how to apply the Baby Doe guidelines;
iii) *the end of medical progress* (1992 to the present). The end of medical and technical progress in neonatology had important moral implications. Researchers asked parents what they really wanted.[3]

These eras reveal the tensions between the technological imperative and moral ignorance or, at least, moral uncertainty. There is no easy answer, but we certainly need to do better.

I would now like to call attention to two points. First, note that, in the second era reconstructed above, doctors did not *know how* to apply specific guidelines. That is why we certainly need a new moral epistemology, as I will argue soon. Second, in the third era, autonomy apparently became the first principle of bioethics overriding all others. Now, giving "parents what they really want" seems no solution at all. Is it right to say that the principle of autonomy, which will be analysed later in detail when discussing autonomism (section 3.2), is the supreme norm of neonatal bioethics? Is it morally right to give the parents of Baby 1 what they actually want even if this disrespects her as a person or is against the Hippocratic moral tradition based on the principle of non-maleficence? Again, it seems that principlism cannot help us out of these tensions; we need to do better. For this reason, I believe we must develop a new moral epistemology grounding morality on *knowing-how* (e.g., to care respectfully) to overcome this state of "exposed ignorance". I hope to

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[3] John D. Lantos and William L. Meadow, *Neonatal Bioethics*, (Baltimore: The John Hopkins University Press, 2006), 18f.

make a contribution to leaving behind this state of affairs with the concept of respectful care based on a new moral epistemology, namely practical cognitivism.

Let me now make another methodological point concerning bioethical investigations right at the beginning of this work. Starting with a case as I did (and I will present others soon) does not imply that I am subscribing to a particularist ethical approach, which denies that there are universal principles. As Hilde Lindemann correctly puts it: “It is often assumed that, when an ethicist works with cases, they are taking a narrative approach to clinical ethics. In this essay, I argue that this is typically not true …”.[4] Thus, I do not intend to do *narrative* ethics or assume any other “bottom-up” particularistic approach to ethics at this point, that is, work from particular cases to general norms. I will follow, however, *some* casuist methodological advice, for instance, discussing real-life cases instead of fictional ones. I will not defend casuistry, which is only committed to *general* norms in analysing paradigmatic cases. On the contrary, I will try to show throughout this work that any bioethical case must be approached with clear moral *universal* principles at hand. I will return to this point later. Consequently, I take particular bioethical cases only as illustrations of the main theoretical points I would like to make here.

What can philosophy say about this case? Well, for one thing, if philosophy has really to do with *wisdom* as its etymology suggests, that is, with knowing-how to live well, it may help us to understand what went wrong in order to avoid similar cases happening again. It must, for instance, provide ways of making *wiser* decisions to avoid conflicts that increase suffering making in this way life better. This is not trivial since wisdom requires us to learn from our mistakes and escape repeating them. In order to achieve that, philosophy may use its critical powers to raise several other questions: (i) What are the values at stake, for instance, were the rights of Baby 1’s parents really disrespected as the family’s lawyer argued? (ii) Did caring require the health team to keep treating the patient or to let her die? (iii) Why did the parents first accept “*palliative*” *care* and then go to court to fight the decision to discontinue life support? (iv) Was *palliative care* conflated with passive euthanasia? (v) If any medical treatment was futile, why was active euthanasia not considered for the baby’s own good? (vi) What were the roles of the media, the ethical committee and the legal system in this case? (vii) Why did the judge not give an immediate order to increase care? These are some general

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[4] Hilde Lindemann, “Context: Backward, Sideways, and Forward” In: Rita Charon and Martha Montello (eds.) *Stories Matter,* (New York/London: Routledge, 2002), 40.

questions we need to answer in order to avoid similar cases happening again. Can a *philosophical* bioethics find a way of avoiding these cases? I believe so and I will try to show how throughout this book by proposing the concept of respectful care based on practical cognitivism.

It seems clear that, on the one hand, giving parents the last word may not be wise at all since they might desire what cannot be provided even by well-developed sciences and advanced technologies in very rich countries such as the US. That is why parents can have a say, but perhaps not the last word. Should doctors have it? I will in this work argue that this is not the case either. There is not yet a Carmentis Machine, that is, a device to ensure 100% certainty on diagnosis about, for instance, the kind of impairments Baby 1 would face if she could be saved.[5] On the other hand, the technological imperative must also be limited by philosophy: from an ethical point of view, it is not true that what *can* be done *must* always be. Technology, as applied science, is basically *knowing-how* to produce artefacts to transform our world. *How* to use them, however, whether to kill or to save lives, is a further and distinct issue, an ethical one. Perhaps the most important question philosophy of technology has to answer is this: how best to decide that what can be done need not be done? The case of Baby 1 shows us that not always what *can* be done (e.g., a transplantation of intestine) *ought* to be. Therefore, science and technology need wisdom to guide them. They need philosophy to show the way to a better life. They cannot be transformed into ends-in-themselves. More importantly, moral values cannot be driven by the needs of science and technology or by the religious convictions of any particular person. I will return this point in the last chapter.

I would now like to illustrate this point by taking into consideration, so to speak, the metaphysical battle behind the scenes in Baby 1's case. Briefly speaking, a health professional team must take a naturalist, a *scientific* stance towards the world, and the doctors were in fact obliged to take this route. That is to say, their religious beliefs must not interfere in their professions. On the other hand, the family and many commentators on the blog about this case, who were trying to influence the family's decisions, had a different worldview, a *religious*, even a fundamentalist one. To recognise that point, contrast what the parents of Baby 1 wrote in their posts, namely, "The clinical statistics for the 23 week old babies are not very good. But our faith is strong and we trust the Lord will see her thru," with this comment on their blog: "God is not the one who has kept

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[5] For an explanation of how such a Carmentis Machine would work see: Dominic Wilkinson, *Death or Disability*? (Oxford: Oxford University Press, 2013), 5f. I will discuss Wilkinson's threshold framework for decision-making later.

this baby alive, MAN is. Babies born at that gestation do not live without aggressive medical intervention … and even with that, most die anyway. You cannot live without an intestine."

Now, philosophy is neither science nor religion and it must remain *agnostic* about metaphysical disputes. Thus, philosophy starts to help in this case in a particular way, namely by showing that much of the struggle around Baby 1 may just have been based on a mistaken contraposition between science and religion. The beginning of wisdom is to recognize the limits of human knowledge. In other words, philosophy sets *the limits* to both science and religion, clarifying their proper domains. Thus, a scientist cannot, for instance, expect miracles; a religious person may hope for a supernaturalist intervention in the causal chain of facts. But the relevant ethical question is this: what about Baby 1 *herself*? To be in the middle of a metaphysical dispute seems certainly detrimental to the patient. Philosophy can help to adjudicate this case by first of all showing that the metaphysical battle may be obfuscating what must be done for the sake of the baby's welfare. That is to say, metaphysical disputes are irresolvable and that means that either a theist or an atheist person (the parents or the medical team) must *care* in a proper way, for instance, by not doing more harm than benefit to the baby *herself*. She is the centre of respectful care. We may conclude, then, that such statements as "To someone to try to play God, it is not right," as Baby 1's mother said, have no role in deciding what to do in her case. They cannot, certainly, be taken seriously from an ethico-philosophical point of view. Consequently, in order to take a non-metaphysical stance towards a particular case, one must embrace *agnosticism* as a basic tenet for building up *a* common, sharable morality. It is a sign of wisdom to keep oneself out of metaphysical disputes, focusing instead on what the cared for's basic needs are.

I would now like to illustrate further how philosophy may help in similar cases by *critically* reflecting on the many moral issues involved. Philosophy's job is above all to put the relevant ethical questions on the table and not necessarily to try to answer them immediately. Now, the case of Baby 1 raises several interrogations about the underlying values, and some of these are *moral* ones: what were the intentions of the family in starting a blog? What kind of comment should be allowed on the internet (for instance, two comments accused doctors of condemning the baby to starvation), and is there a way of assessing them? Why did the parents *delete* some comments posted on their blog, were they trying to manipulate the public perception of the case? Do patients have a duty, not only a right, to confidentiality? What is the role of blogs in medicine, for example, can they be used to disclose information to patients? Should we create, in the name of transparency, a record of patients through publically accessible blogs? Could we ever think of a "public follow up system" for doctors and nurses anywhere to give their opinions on this and on similar cases?

Here are some more questions: what is the power-play role of the media in a case like this since the baby's family intentionally called a local TV channel after being instigated by comments on the blog? Were AA News and Channel X (not their real names) too sensationalist in reporting the case? Who manipulates whom: the media by "selecting" information or the public by "calling" the media when it is convenient to produce alarm or scandals? How can the media nowadays be more impartial and not surrender so easily to ideologies?

To continue questioning: what was the role of the legal system in this case? What kind of justice can be done by court order? Saving the baby's life or transplanting organs (intestines) even if it is pointless from a medical point of view? If the defendants requested a guardian *ad litem* to ensure the best interests of the child, what was left of the patient's autonomy in this case where she was legally represented by the parents? Were Baby 1's parents incompetent? Were the patient's rights completely violated, as the family's attorney argued in an interview for a TV channel? Did the court *disrespect* the baby herself by not giving an immediate order to increase *care*? Is this *fair* from a social, political point of view?

The questions do not stop there: what is the role of the (bio)ethics committee in this and similar cases? What kind of role may a paediatric ethics committee have? Must it have just an advisory and *educational* role or be part of the *decision-making* process also? In other words, must it have just a revisionary function or also the capacity to recommend a course of action? What about the composition of the ethics committee? Does it not represent corporate interests and protect the health professionals' interests given that the majority of its members come from the health institution itself? Is this composition of an ethics committee *ethical* after all?

What kind of principle (or value etc.) did the U. of A. apply to reach a conclusion about this particular case? Did it apply, for instance, the Hippocratic principle "first [or above all], *do no harm*?" as having an absolute status? If the answer is "yes" because any treatment is futile, that is, without therapeutic effect, would it not have been better *to euthanize* the baby instead of *withdrawing her food*?

There are other institutional questions: is a hospital entitled to refuse treatment if the parents have no proper health insurance (the patient was first transferred from another facility for insurance reasons and then denied a new transfer by the insurance company)? Is this fair from a *social* point of view? Should health caregivers withdraw treatment when it is futile without the patient's consent for economic reasons? If not, are they giving the appropriate, deserved care?

Consider also these questions: should they have given more treatment in the Baby 1 case, including more morphine (possibly hastening death), if the parents or the court had requested or demanded it? Were the doctors "playing God" (in the sense of deciding who should live or die), as the mother said in her interview with the TV channel? Would there have been a place for religion in this case if Baby 1 had happened to be in another facility? Were the parents and doctors rather disrespecting Nature by keeping Baby 1 alive by all means? Should the health team have tried an *experimental* transplantation, even if it is a risky and very expensive one, using the patient as an object (a mere means) of scientific research or have carried out a surgery to rip out parts of her intestine, which is also an invasive and perhaps unethical procedure, for teaching purposes only?

Certainly, there are other questions. If it is true, as the U. of A.'s unique short note on this case states, that "they met with the patient's parents and determined the most appropriate and ethically responsible course was palliative (end of life) care," why did the parents change their minds and go to court? How did the parents give the informed consent? Was it signed? Was clear information disclosed by the health team? Were the parents not entitled to change their minds and to demand the respect that the baby deserved, the care she really needed? Did they understand that palliative care *really* meant end of life care and, in this case, *withdrawing food*? It seems that the answer to this question was negative, as even the U. of A. defendant document recognizes, then, was this not a clearly disrespectful and uncaring attitude? And so on and so forth ...

I do not hope to answer all these questions in this book, but, as a philosopher and not as a professional bioethicist, I will certainly contribute to raising some more. My special concern is to ask whether what was absent was *respectful care* and how things could have turned out differently if Baby 1 had been cared for respectfully. Before trying to build up this concept, I would like to present in a more detailed way the idea of a philosophical bioethics and what we can expect from it in discussing the meta-ethical and normative bases of bioethics.

1.2 The idea of a philosophical bioethics

I would now like to say a few preliminary words about the conception of bioethics that I will use throughout this work. Simply put, I take bioethics to be part of ethics understood as a *philosophical* discipline, not a scientific or theological one. There is clear evidence that bioethics was born as a philosophical project. For instance, some have argued that bioethics is best understood in terms of the knowledge needed to use scientific knowledge. For one, van Potter, the American oncologist until recently believed to have coined the word 'bioethics,' held that we need *a new kind of wisdom*, namely "'the knowledge of how to use knowledge' for man's survival and for improvement in the quality of life."[6] Bioethics was conceived in an age when technoscience was not always used to provide a better life: the Cold War could have led to the destruction of humanity; industry was polluting the environment etc. Thus, the origin of bioethics was a response to the misuses of technology demanding more wisdom and not only more scientific knowledge. In the same spirit, Arne Naess proposed the word 'ecosophy,' calling for a *wiser* attitude towards nature as a whole.[7] The common assumption was the need felt for a new relation towards the environment and non-human animals to overcome the dichotomies and radicalisms introduced by modern sciences and their unwise technological applications. These misapplications were driven by a positivist or scientificist worldview. Science and technology can, as was tragically proved by the two world wars, be used to destroy humanity, if not life as a whole on this little blue planet. This is definitely not a sign of wisdom, and we are in no better position nowadays. We should not forget that these menaces are still hanging around, as Professor Stephen Hawking warned us recently, namely that the development of full artificial intelligence (AI) could spell the end of the human race. To avoid artificial intelligence destroying us, we need to enhance our wisdom, not only our scientific knowledge. I will return to this point in the last chapter.

It seems then a mistake to speak in terms of "biomedical ethics or bioethics" as if they were the same thing as some important bioethicists still do.[8] As we know today, the word 'bioethics' was used for the first time back in 1927 by Fritz Jahr, who stated the following principle:

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[6] Rensselaer van Potter, *Bioethics*, (New Jersey: Prentice-Hall, 1971), 1.

[7] Naess is reported to have said: "What we need today is a tremendous expansion of ecological thinking in what I call ecosophy. *Sophy* comes from the Greek term *Sophia*, 'wisdom,' which relates to ethics, norms, rules, and practice. Ecosophy, or deep ecology, then, involves a shift from science to wisdom." *Apud* Bill Devall and George Sessions, "Deep Ecology" in: James Sterba, *Earth Ethics*, (New Jersey: Prentice Hall, 2000), 155.

[8] Unfortunately, this reductionist view is still widely held, for instance, by Beauchamp and Childress in their book *Principles of Biomedical Ethics* (Oxford: Oxford University Press, 2013), p.vii.

“Respect every living being on principle as an end in itself and treat it, if possible, as such.”[9] I will comment on this principle later, in chapter 7. What we need to bear in mind, then, is that *special bioethics*, both clinical and academic, conceived as a practical discipline dealing with biomedical issues, came to be predominant leaving a more holist approach, based on wisdom and on a concern for life as a whole, aside. Thus, to avoid misunderstandings, I will use the expression ‘holistic bioethics’ to refer to Jahr’s principle as well as Potter’s project of a ‘global bioethics’. I will reserve the expression ‘global bioethics’ to refer to bioethical issues in the international arena, for instance, whether informed consent is needed only in developed countries or also in other nations with no specific legislation requiring it. Thus, I will use the expression ‘special bioethics’ to refer to the moral issues surrounding human experimentation, for instance, in the biomedical sciences. Finally, I will use *philosophical bioethics* for an ethical discipline based on wisdom connecting all these dimensions, that is, special, global and holistic bioethical issues.

This is perhaps the right place to say something more about the origins of bioethics and why it began to be seen just as a deontology or a professional ethics for scientists, mainly in the life and medical sciences, instead of a concern for life as a whole based on wisdom. The main reason was the extraordinary advances in the past 40 years in areas such as the above referred to, namely neonatology. But stories like Baby 1’s should make us rethink the foundations of special bioethics and discuss its basic principles, especially the role that individual autonomy, this “all-American value,” has come to play nowadays. Since the publication of the *Belmont Report*, a US official document, which will be carefully examined in the next chapter, there has been widespread disagreement about the best formulation of the fundamental principles of special bioethics, namely *respect for persons*, *beneficence* and *justice*. These are, however, ethico-philosophical problems; not scientific ones.

Despite the fact that we may use the word ‘ethics’ as a synonym for ‘morals’ (the words are simply interchangeable), we need to establish a distinction between *studying* morality from a philosophical point of view and simply *moralizing*. Consequently, ethics is taken here as a theoretical discipline, as a philosophical reflection upon moral phenomena including bioethical issues such as whether active euthanasia in Baby 1’s case was not a better option. We need, then, a clearer understanding of ethics to clarify the nature of bioethics itself.

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[9] Fritz Jahr, “Bio-Ethics”. In: Amir Muzur and Hans-Martin Sass (eds.), *Fritz Jahr and the Foundations of Global Bioethics*, (Berlin: Lit Verlag, 2012), 4.

Before presenting the main domains of ethics so defined, I would like to point out some differences between ‘ethics’ and ‘morality’. As a philosophical discipline, ethics is based on wisdom, that is, on knowing-how to live well. Ethics is a philosophical and not a scientific enterprise, which starts with a distinction between facts and values and from the assumption that the latter cannot be justified only empirically. As the reconstruction of the Baby 1 story showed, we need to separate facts and values to better understand the particularities of the case in order to know what to do and, more importantly, *how* to do it. There may be sciences of moral phenomena, for instance, a sociological and statistical study of how many premature babies below 500gr do survive in a particular country (US or Brazil or UK), but bioethics is not among them. Ethics is about what we *must* or *must not do*, for instance, whether it is morally permissible to kill a chronically ill baby instead of let her die, and this is not an empirical question. That is to say, it does not depend on what is prescribed in a particular jurisdiction.

A moral system, on the other hand, may involve a set of habits, rules, qualities of character etc. of a group or society, which guide behaviour towards some conception of the good life. Consider Roger Crisp’s characterization of a moral system:

> A set of cognitive and conative states, including beliefs, desires, and feelings, which leads its possessors among other things to (*a*) view certain actions as wrong (that is, morality forbidden) and hence to be avoided, (*b*) feel guilt and/or shame as a result of performing such actions, and (*c*) blame others who perform such actions.[10]

In this sense, as a matter of fact, there are many moral systems, many moralities: Jewish morality, Christian morality, socialist morality, Piraha’s morality, Buddhist morality, Islamic morality, Hindu morality etc. etc. Whether there is a *common* morality is a further and distinct question. I will return to this point in chapter 4.

We must bear in mind, however, that ethics is *not* moral theology, that is, the application of a particular religious doctrine to the problems of life. It may be misleading, then, to assume from the very beginning that all these moral systems have their own particular bioethics. Of course, a specific religion may inform some bioethical issues such as whether euthanasia is permissible, but its beliefs and values cannot be universalized. Thus, pluralism has a limited role to play in a common morality. A principle such as “first, do no harm” may have an *a priori*

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[10] Roger Crisp, *Reasons & the Good*, (Oxford: Oxford University Press, 2006), 9.