HEALTH CARE ETHICS

Theological Foundations, Contemporary Issues, and Controversial Cases

REVISED and EXPANDED

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Created by the publishing team of Anselm Academic.

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Printed in the United States of America

7034

ISBN 978-1-59982-103-0

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PREFACE

This book is intended as a theologically inspired introductory text in health care ethics geared primarily toward college students but also appropriate for medical, nursing, and other students in health care-related fields, as well as health care practitioners. Our goal in writing this book is to encourage moral reflection and moral discourse on ethical issues in health care rather than resorting to ready-made and prescriptive answers to concrete dilemmas. This book examines real-life concerns and issues that confront real people every day. It is an applied ethics textbook written by theological ethicists working in health care.

We believe this book offers three elements that set it apart from similar texts. First, this book does not assume extensive knowledge of theology, ethics, or medicine on the part of readers. Second, this book includes case studies that we have confronted in our work, giving real-life relevance to the text. These cases are intended to show how particular circumstances have an effect on ethical decision making. Finally, each chapter provides a list of further readings and multimedia aids, such as documentaries and movies, that touch on the core themes of the chapter and that, with the case studies, can be incorporated easily into creative teaching and learning strategies.

As with the first edition, this revised and expanded edition of the text has two main parts, beginning with theological and ethical foundations (chapters 1–3), followed by concrete ethical issues in health care (chapters 4–12). The foundations lay the groundwork for the discussion of ethical issues that follows in subsequent chapters through, among other ways, outlining a normative basis that provides a backdrop or point of reference against which we can evaluate the ethical issues. In our experience as college teachers and ethicists within health care institutions, we have learned that it is pointless to discuss controversial issues without some kind of normative basis.

Lacking such a basis, ethical discussion inevitably degenerates into individual relativism.

Two things should be noted up front about our normative basis. First, though it is grounded in some values and concepts that are central to the Catholic moral tradition and Catholic social teaching—such as human dignity, justice, and human flourishing—our normative basis is not exclusively Catholic, and this book is not intended as a textbook on Catholic health care ethics. Second, our normative basis is not a moral method per se. That is, it does not provide a methodological process for ethical decision making. Instead, it presents a picture of who we ought to become as persons living among others in the context of community. The central concern of our normative approach is human flourishing and right relationships. Although principles and virtues provide some objective basis for ethical decision making, our normative approach is rooted in a holistic view of the person and principally concerned with the role of discernment in attaining human flourishing.

All the chapters that remain from the first edition have been updated with new material, cases, and suggested readings and multimedia aids. Some of these chapters will look slightly different from the first edition because new and emerging topics have been added. For instance, in chapter 5, we now include a discussion about the considerations of costs when assessing treatment options for critically ill newborns; in chapter 9, we have added a section on pharmaceutical and device manufacturers' involvement in clinical research, and the conflicts of interest that can arise for investigators or institutions; in chapter 10, we have added a discussion on the 2009 revision to the *Ethical and Religious Directives for Catholic Health Care Services* and the implications for treatment decisions related to artificial nutrition and hydration; and in chapter 11, we have added a section on advance care planning and the critical role it plays in ensuring patients approaching the end of life receive care that conforms to their personal values and wishes.

In addition to this updated material, we have condensed the four foundations chapters from the first edition into two and added a new chapter to the foundations section on professionalism and the patient-professional relationship. We felt this was important for two primary reasons, namely, (1) the first edition lacked a sustained

discussion on this topic, and several health care professionals who read our book noted this absence, and (2) health care ethics unfolds most immediately in the privacy of the patient–professional relationship, and ethics can provide balance to the inherent unevenness in this relationship by critically shaping how we understand the nature of the relationship itself. Coupled with the condensed foundations chapters from the first edition, this discussion of professionalism and the patient–professional relationship adds depth to the ethical analysis of the issues that follows in subsequent chapters.

Also new in this edition is chapter 12, which deals with health care reform. Given the significant ethical concerns that have been raised about the American health care system in recent years—concerns over access, limited resources, high costs, racial disparities, quality, and safety—we simply had to confront this issue in this revised and expanded edition. Though we do not delve into any great detail on the recently passed Patient Protection and Affordable Care Act, we do consider the issue of health care reform from an ethical perspective, a perspective that has been sorely lacking in the current American debate.

We must note one last thing. As with the first edition, this book is the product of four authors. Consequently, you will once again encounter four different voices and writing styles. Though we all work from the same foundations, there are differences in how extensively and explicitly we apply the normative basis to the issues discussed. Similarities will exist across the chapters in terms of content and structure, but subtle differences will be perceptible, as well, given the collaborative nature of this text.

—*Michael Panicola and David Belde*

CHAPTER 2

The Bases for Our Decisions and the Role of Discernment

Michael Panicola

A Proposed Normative Basis

So far we have defined what ethics is generally, described what health care ethics is specifically, and considered how we tend to approach ethical situations. Now we will ask, on what do we base our decisions? Whether we tend toward virtues, principles, consequences, or some combination of the three, underlying our decisions is a *normative basis*. Without a normative basis, we could not determine what virtues we should seek to develop, or what principles apply, or what consequences are most desirable. In short, there would be no ethics because there would be no criteria for making ethical decisions. So in this chapter we take the next, critical step and outline a normative basis that will shape how we view all moral matters. Sketching a normative basis is a tall task, and there may be disagreements when we get down to particulars—after all, we are attempting to articulate the goals of human life, the virtues and characteristics that ought to define us as persons, and the principles that should guide our actions in concrete situations. Yet we know that we need a normative basis and that we share many common normative beliefs.

Describing a Normative Basis

A normative basis is something that gives us insight into who we should become as persons (BEING) and how we should act in

relation to others, namely, people, God, and creation (DOING). A normative basis is a framework, point of reference, or backdrop against which we make ethical decisions and evaluate who we are as persons, the morality of our actions, and the effect of our actions on others. It may help to think of a normative basis in terms of something familiar, like basketball. Basketball referees call fouls on players. Although not every foul called may be warranted, fouls are called nonetheless based on some idea of how basketball players should conduct themselves while on the court. Over the years this idea of how the game should be played has evolved and been codified in a rulebook that referees use to distinguish between appropriate and inappropriate behavior. In essence, this rulebook is a normative basis. A normative basis need not be as detailed or as rigid as a basketball rulebook to serve as our blueprint for living morally. Human experience, revelation, community life, and other sources have afforded us some idea of who we should become as persons and how we should act in relation to others. Ethics is nothing more than making ethical decisions and judgments in light of this idea, this normative basis.

The Goal of Human Life

As we pointed out in chapter 1, we all make use of some normative basis, whether we know it or not. In fact, most everything we do socially or interpersonally is guided by a normative basis. Nevertheless, we do not all lead good, moral lives or act ethically in every situation. How can this be if we all have and use a normative basis? There are many reasons for this. Experience and personal reflection tell us that we are imperfect people, beset by physical, intellectual, psychological, moral, and spiritual limitations, who live within a social context that is at once good but also sinful. Because of this, like Saint Paul, we sometimes lack the moral strength and courage to do the good we desire and instead do the bad that we know we should not (see Rom 7:19–20).

Practical reasons also account for our not acting ethically all the time. Sometimes we do not know what is the truly right or good thing to do, other times we may lack the capacity or energy to inform our conscience adequately to make the best ethical decision. Another reason, ever-present in our impatient world, is our tendency to be

shortsighted about matters of ethics or morality, our failure to consider the big picture and to link our more immediate goals with the ultimate goals for which we are striving. Some people call this "moral myopia."

Every action we perform in life is directed toward particular goals. We brush our teeth to avoid cavities and to eliminate bad breath; we take classes in college to fulfill the requirements for graduation and to get a good job; we sleep to rejuvenate ourselves and to avoid getting sick; we work to have the means necessary to live a decent life and to develop our talents; we eat to be nourished and sustained physically; we see movies to be entertained and to escape from everyday life; we vote in democratic elections to help shape social structures and to ensure that our rights are protected.

Our moral actions especially are directed toward goals. From an ethical perspective, however, it is important to recognize that beyond our more immediate goals is an even more basic or underlying goal that ought to provide the overall direction for our lives and guide our decisions. The first step in constructing a normative basis is to discern what this goal is, the goal for which we are ultimately striving as human beings. Individuals and communities have struggled with this question for thousands of years. People often say that the ultimate goal of human life is to have fun, to be successful, to be smart, to be compassionate, or to love others. These are indeed good goals for which we should be striving. Without these, life would not be nearly as meaningful. However, all these goals in various ways point to an even more fundamental goal, that of human flourishing. Ethically speaking, human flourishing supersedes all other goals, it is the goal to which all others should be directed. Think about it: we do not want to be successful just so we can feel good about ourselves and receive accolades; we do not want to be smart just to impress people or score high on an IQ test; we do not seek to be compassionate so people will say how kind we are. Rather, we pursue these goals because they offer us the possibility of living a good life, a life in which we flourish as individuals in relation to other people, God, and creation.

We encounter problems in our moral lives when we make ethical decisions without attending to the goal of human flourishing. When this happens our ultimate goal as human beings becomes subordinated to some other, more immediate goal, and our pursuit of human

flourishing is often undermined as a result. Take, for example, Case 1C in chapter 1 involving the abusive supervisor. If we focus on the more immediate goals, we might not report him to a higher-ranking executive, although it is probably the right or good thing to do. Think about it: you value your job, make decent money, have bills to pay, enjoy the lifestyle to which you have grown accustomed, and would have difficulty finding another job. If your goals are limited to these issues and do not include human flourishing, your choice would be clear. However, when we compare these against the goal of promoting our own well-being (dignity, character, quality of life) and that of others, as well as the good of the community, these immediate goals probably would take a backseat to doing the hard but ultimately right thing.

This is how a normative basis functions in ethics and acts as a corrective to moral myopia: it helps us "zoom out" so we see the bigger picture and make ethical decisions accordingly. It is like the Google map feature that many of us use for driving directions. While the map can zoom in to show us the street and particular area we want to find, it can also zoom out to give us a sense of where we are and where we are headed. To live a good moral life in relation to others, it is critical that we "zoom out" by considering our more immediate goals against the backdrop of human flourishing and other morally relevant features.

Understanding Human Flourishing

It is pretty hard to deny that human flourishing is the overarching goal of human life, as we pointed out in chapter 1. What is debatable is what it means to flourish as human beings. This is where we run into challenges, because people can and do have different conceptions of human flourishing. Many of the ancient Greek philosophers who considered this question spoke of human flourishing in terms of *eudaemonia*—what we might call happiness. They believed that happiness is the only goal we seek for itself alone and never for the sake of something else.[1] The term *happiness* could easily be misconstrued to refer to having our desires fulfilled or achieving pleasure in every situation. This is not what the Greeks had in mind. Happiness for them was generally understood as having a well-formed character that allows one to live a life of virtue.

Think about what human flourishing means to you and what you think you need to flourish as a person. In the space provided below, list ten things that you feel are necessary for living a good life, a life of flourishing. These could be such things as money, a big house, health, sports, music, people or love, friendships, community, peace, religion—the choice is yours.

______________________ ______________________

______________________ ______________________

______________________ ______________________

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If you were forced to live without five of the ten items you selected above, which five would be most important for human flourishing? List them here.

______________________ ______________________

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Now go one step further and consider which two of the five remaining items are most important for human flourishing. Write them below.

______________________ ______________________

This can be quite a difficult exercise because it is hard enough limiting the items necessary for human flourishing to a list of ten, let alone two. Interestingly, as we do this exercise with students, health care professionals, and others, the two most common final items are

health and relationships (which you may have listed as a specific person, your family, your friends, community, or something equivalent). Health is an obvious choice; without health it becomes difficult to pursue any goals or ends. Relationships, though, are another matter altogether. What makes relationships so essential for flourishing as human beings? This is where the Christian understanding of human flourishing is so instructive.

Although the Greeks equated human flourishing with eudaemonia, translated as best we can in today's terms as "happiness," for Christians human flourishing is understood as love of God. What this means in practical terms is that we live truly rich and full lives when we love God in all that we do, when we direct our lives totally to loving God. Jesus made this clear when responding to the Pharisee who asked him what the first and greatest commandment was. Jesus' simple response was to "love the Lord your God with all your heart, and with all your soul, and with all your mind" (Mt 22:37). The Judeo-Christian tradition tells us that we have been created out of God's unconditional and unyielding love and that we are directed toward God as our ultimate end. Through human life we enter more fully into communion with God by loving God and giving glory to God in how we live our lives.

Admittedly, saying that human flourishing means love of God is vague, especially because ethics is a practical discipline. How do we love God when we do not necessarily encounter God immediately? Jesus' response to the Pharisee provides us with an answer to this question. After saying that we should love God with our whole heart, soul, and mind, Jesus went on to say that there is a second commandment, which is like the first: "You shall love your neighbor as yourself" (Mt 22:39). The second part of Jesus' statement is as important as the first, for in it Jesus draws the link between relationships and human flourishing. Human flourishing, understood as love of God, is pursued most tangibly within the context of relationships. We encounter God primarily through relationships with others, though we can also encounter God in other ways (e.g., prayer, personal reflection, meditation, and within nature). From an ethical perspective we cannot love God and flourish as human beings without loving our neighbor as we love ourselves. Saint John also made this clear in describing how we love God in the context of human life: "Those who say, 'I love

Professionalism and the Patient–Physician Relationship

Mark Repenshek

What Does *Professionalism* Mean?

Recall the last time you were at the doctor's office. Regardless of the reason, it is likely you extended a good deal of autonomy to your doctor without question. By autonomy, we mean acceptance of a professional's judgment on matters within his or her expertise.[1] Think again of that doctor's appointment. You likely extended professional autonomy to the physician in at least three areas: (1) determining your specific needs relating to the reason for the appointment, (2) determining the likely outcome of actions that might be taken regarding those needs (e.g., further testing, a prescription, consultation with a specialist, or further intervention), and (3) judging which course of action is most likely to best meet your needs. This is not to say the physician made every decision for you, but she likely made numerous decisions on your behalf within the scope of her expertise, with a high degree of trust extended on your part. This account of a typical office visit to a doctor exemplifies the concept of professionalism.

Some may consider professionalism to derive from an oath or membership in a society or perhaps even from being "called" to serve in a particular manner. Although these are important aspects of professionalism, none fully defines the concept. Each criterion suggests that being a professional is contingent on some personal commitment or admirable characteristic. This narrow focus misses two key aspects of professionalism, however: dialogue between a

professional group and the community it serves, and the ethical obligations over and above what "the marketplace" or a contract would demand.

In this chapter we adopt a traditional approach to the term *professional*, which refers not only to specialized expertise but also to particular moral commitments associated with a practice. In the case of the physician, we discuss expertise beyond that derived from time spent in medical school and residency and focus instead on the broader culture and infrastructure supporting medical education. With regard to moral commitments, we discuss both the privileges of the physician and the physician's obligations to those served.

Aspects of Physician Professionalism

In 2002, the American College of Physicians (ACP) and the American Society of Internal Medicine (ASIM) jointly published a charter on physician professionalism. Walter McDonald, then executive vice president and CEO of ACP-ASIM, termed the charter "a call to individual physicians to reaffirm their dedication to the welfare of their patients and to the profession to collectively work to improve health care for all."[2] Of particular interest here is the brevity of its impetus, namely, to combat a tendency in current medical practice that tempts physicians "to abandon their commitment to the primacy of patient welfare."[3] What could have caused this turn in medicine that shifts physicians' focus away from patients? What is competing for physicians' attention? Are there factors other than patient welfare influencing physician behavior? Are physicians obligated as part of their medical training to maintain a contract with society? What is the basis of that contract? Given the specialized knowledge that physicians have, could that knowledge be used for a good other than health and well-being? Will patients be at risk should physicians not reaffirm their "dedication to the welfare of their patients and to the profession to collectively work to improve health care for all"?

Each of these questions concerns a specific aspect of professionalism. We discuss three important aspects of professionalism here: (a) important and exclusive expertise, (b) autonomy in matters of expert practice, and (c) obligations of professions and professionals.

Important and Exclusive Expertise

Medicine is vital to the health and well-being of people. The ultimate reason for the profession of medicine is the complexity of the specialized knowledge the profession controls.[4] Despite Web-MD™, Medline™, or any other Web-based source of medical knowledge, this knowledge is not easily understood by the general public, and consequently the medical profession is given significant control over its use. Thus, the medical profession requires integrity of information, proper application of information, and continued testing and dissemination of information (i.e., clinical trials). Finally, the profession is obligated to transmit medical knowledge to the general public, to patients, and—through teaching and mentoring—to future practitioners.

Medical expertise has two key attributes that qualify it as a profession: it is cognitive and practical. The medical profession depends heavily on those already expert in the field to teach and mentor the next generation of professionals. Given the complexity of medical knowledge and the difficulty in teaching and mentoring its use, those able to perform both tasks well are few. Add to this the responsibility to care for other humans, and the high stakes of physician professionalism become abundantly clear. The following case study will help to illustrate the many pressures unique to the physician in his or her development as a professional.

Case 3A

Early in his medical school education, Jakob knew he was an exemplary student. He was often sought out as a study partner, and many of his classmates turned to him for his knowledge on particular subjects. This continued into his residency at one of the nation's leading academic medical centers in orthopedic surgery. Jakob quickly progressed through his surgery rounds, grabbing the attention of many faculty members with his skill and bedside manner.

During Jakob's second year in his surgery fellowship in orthopedics, he became concerned about a colleague who was

cont.

Case 3A *cont.*

also a good friend. For months Jakob had been concerned about his friend's bedside manner, but recently he had been struck by his colleague's failure to fulfill some of the more advanced technical aspects of certain procedures. Jakob knew that eventually the faculty would need to decide whether his friend was cut out for orthopedics, but he really wanted his friend to progress through with him. In fact, they had often talked about how great it would be to practice in the same city, sharing referrals, knowledge, and new cases.

As things grew worse for Jakob's friend, the friend started using stimulants to stay awake longer to get extra cases and to study harder in areas where he continued to falter. Jakob felt compelled to assist as much as he could but was worried about his friend just getting by. Jakob started to ask himself some troubling questions: Would he ever send a patient to his friend? Would he feel comfortable with his friend's skills were Jakob and he seeing the same patient as partners in a practice? Would Jakob want his friend operating on one of his family members?

As chief resident, Jakob was uncertain as to the next step to take but felt compelled to approach faculty about his friend and the potential risk he posed to future patients. Jakob was also uncertain whether this was appropriate, given the culture of medicine, and was concerned that he would lose his friend as the result of such an inquiry. Jakob had seen colleagues cover for each other many times in far worse situations (involving substance abuse). Also Jakob wondered if this was indeed his responsibility. Shouldn't faculty handle this? Wouldn't they notice his friend failing in skills at the mastery level and decide not to move him on, instead suggesting a different course of surgery? Besides, someone has to be at the bottom of the class, and that person is still considered a doctor.

Ultimately, if Jakob were to see this as a matter for faculty and not for him as chief resident, would Jakob be faithful to the privilege of important and exclusive expertise accorded to the medical profession?

Case 6A

Sam and Camory, happily married for more than eight years, have been trying to have children for some time without success. Examination by a physician reveals that Camory has blocked fallopian tubes, and surgery would not rectify the condition—quite simply, they are unable to have children through conventional means. They strongly desire to have a child that is their own genetic offspring, and although their insurance does not cover reproductive interventions other than fertility drugs, they are willing to make the financial sacrifice. Sam and Camory's deep longing for children leaves no reason to doubt they will be loving parents. To a certain extent they also feel their marriage is lacking because they are unable to have children. Faced with this situation, IVF seems like the best solution. Camory is a prime candidate for the intervention because her uterus and ovaries are healthy. Also Sam has an adequate sperm count and the sperm function properly. Thus neither a donor nor surrogate will be necessary. IVF seems to offer them a good chance at having genetic offspring.[17]

This is a common situation in the context of reproductive technology. Like so many other individuals and couples, Sam and Camory's deep longing for children and feelings of emptiness stem from problems related to infertility. IVF offers them hope of overcoming these challenges. The question is whether it is morally acceptable for Sam and Camory to pursue this reproductive intervention in an effort to have a child. The first thing to consider as we think about this case is how having a child through technological means will affect their relationship. Will it bring them closer together in their love for each other? Will it satisfy the deep longing and fill the emptiness they have? What kind of parents will they be? Will their love for each other be reflected in how they care for the child should the procedure succeed? Given what we know, it seems that Sam and Camory's relationship could be enhanced by having a child. Though happily married for eight years, they long to have a child, which they would very

much welcome into their lives and for which they would take full parental responsibility. Yet is this adequate? This would suggest that any committed, married couple experiencing infertility could pursue reproductive technologies if they are willing and able. Our normative basis requires a deeper look.

The use of a donor or surrogate is not an issue here. If they were to have recourse to a donor or surrogate, we would have to object given the potential negative effect on the marriage, offspring, and society at large.

We also must consider whether the burdens on Camory are acceptable. Is Camory aware of what IVF entails in terms of fertility drugs, egg harvesting, the transfer of multiple embryos, and the possibility of multiple pregnancies and associated risks? If her physician explained all this to her and she is willing to accept the burdens, it is hard to argue that these burdens are too heavy, especially because she will not be asking another to carry these burdens for her (through egg donation or surrogacy).

How will Sam and Camory's decision affect their financial well-being and the common good? Because their health insurance does not cover IVF, they are going to have to assume all the costs. We don't know what effect this will have on them, but if they can reasonably afford it without undermining their overall well-being, then it would be hard to deny them this opportunity on these grounds. If they were receiving help or coverage from their health plan, one could argue that their use of IVF could drive up the overall costs of the plan and result in increased premiums for all members, but that is not the case here.

Will Sam and Camory elect to create multiple embryos and choose to freeze any that are not transferred in the first cycle of treatment? Respect for early human life demands that they create only the number of embryos that could be safely transferred for implantation without having recourse to cryopreservation. If they insist on this point, we would have no objections on these grounds.

Finally, we must consider whether there are any viable alternatives for Sam and Camory, such as becoming foster parents or adopting. Would one of these options satisfy their deep longing to have a child? Either of these options would allow Sam and Camory the opportunity to be parents while at the same time providing a safe, loving home for a child in need. For many people with problems of

infertility, though, these are options of last resort because of their strong desire to have children of their own genetic lineage. Though ideal, these options seem to demand more from Sam and Camory than we can reasonably expect.

The case of Camory and Sam again reveals that one must not isolate individual decisions about reproductive interventions from the broader context of human flourishing and right relationships. We may not have satisfied a desire for definitive answers to the ethical questions raised by RTs, but hopefully through the discussion of the ethical issues and the analysis of this case we have shown what needs to be considered. Perhaps the most we can say about reproductive interventions outside of concrete situations is that there are certain circumstances in which their use may be morally permissible. Like many of the Christian religious traditions noted above, the circumstances we would find acceptable would be within the context of a loving, committed marriage, where there is no recourse to donors or surrogates, where the health and safety of the woman is protected, where embryos are not destroyed, where financial burdens are borne by the couple, and where the common good is not negatively affected. The use of RTs in such a context and under these circumstances would be conducive to fostering right relationships and ultimately contributing to the well-being of the married couple and their children without undermining that of others.

Now consider another case:

Case 6B

A 35-year-old female contacts you regarding a letter she received from an infertility clinic where she contracted services for in vitro fertilization some fifteen years ago. The letter states that she has five embryos frozen in cryopreservation and her agreement is due to expire in six months. The infertility clinic is asking what she would like to have done with the embryos at the expiration of the contract. The contract

cont.

Case 6B *cont.*

stipulated that she could continue the cryopreservation process on a year-to-year basis at $300 annually. The woman was unaware that she had any embryos still in cryopreservation and is stunned to find out that she is now responsible for determining their fate. She is currently divorced from the man whose sperm was used in the in vitro fertilization process and she has sole custody of their children.

At the same time, the former husband received the same letter due to legal stipulations in the informed consent process at the time of the in vitro process. The letter states the mother has the right to determine what to do with the embryos (which includes offering the embryos for adoption or donating them for research purposes), unless she chooses to have the embryos destroyed. In the latter case, the partner's consent would be necessary, regardless of marital status. Further complicating the matter is that the ex-husband's visitation rights had been taken away due to allegations surrounding child neglect and abuse, and the woman does not want to reopen a custody battle in the courts for fear her ex-husband might gain visitation rights. Also she had recently lost her job and, although she has found new employment, it pays substantially less. She says she is barely getting by and is not financially prepared to handle the $300 fee to keep the embryos in cryopreservation. The woman tells you she is a Roman Catholic. She has not gone to church in quite some time but is aware of the Catholic Church's position on abortion and does not feel it is right to simply dispose of the embryos. Furthermore, destruction of the embryos would require the husband's consent, and she does not want to reestablish contact if avoidable.

Despite financial hardship, does the divorced couple (or at least the woman) have an obligation to maintain the embryos in cryopreservation? Or should the woman simply offer the embryos for adoption to avoid reestablishing contact with her former husband and the corresponding risks to her children should contact occur? Is there another ethically permissible option?

Beyond Assisted Reproduction: Ethics and Prenatal Testing

The ethical issues and questions brought about by RTs are not limited to those ARs that people may use to try to become pregnant. RTs also enable us to gain knowledge about the child with which one has already become pregnant or may become pregnant. Indeed, many ethical issues arise in the context of what ought one to do in light of this knowledge given a current or desired pregnancy.

Issues in Carrier Testing and Screening. The acquisition of knowledge is not in itself a justification for CT or CS. Yet such technologies can be extremely beneficial to individuals with a genetic predisposition to a particular disease. For example, those with the gene for xerodermapigmentosum are extremely sensitive to ultraviolet radiation, and exposure to such radiation is likely to lead to a form of melanoma that is usually incurable. However, avoiding such exposure usually allows one to avoid developing melanoma; knowledge leads to benefit.

Take, however, the case of Duchenne muscular dystrophy (DMD), an X-linked recessive disease. Because females have two X chromosomes, a female can be a carrier of a DMD gene mutation but will usually not develop the condition, because she has a normal copy of the gene on her second X chromosome. Knowledge of being a carrier for this condition will in no way lead to treatment or cure. In other words, no way of preventing the disease is known, and early diagnosis and intervention makes no difference in the outcome of the disease progression. Some may wish to know whether they are a carrier of the deleterious gene so as to make informed decisions about marriage, childbearing, and lifestyle. Others might prefer blissful ignorance. This raises an ethical question: in cases where treatment or cure cannot change the outcome of the disease progression, should genetic testing be done as a matter of responsibility to future offspring and society? That is, does an individual with a terminal genetic diagnosis have an obligation to undergo testing so as not to reproduce? If so, the deleterious gene would not harm future offspring, and the lineage with the genetic anomaly would cease.[18]

The normative basis offered in this work suggests that the question of what constitutes right relationships between parent and child