

BIOETHICS

A REFORMED LOOK AT

LIFE AND DEATH CHOICES

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Grand Rapids, Michigan

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Library of Congress Cataloging-in-Publication Data

Groenhout, Ruth E., 1962-

Bioethics: a reformed look at life and death choices / Ruth Groenhout.

p. cm.

Includes bibliographical references.

ISBN 978-1-59255-263-4 (alk. paper)

1. Medical ethics—Religious aspects—Christianity. 2. Bioethics—Religious aspects—Christianity. 3. Christian ethics. I. Title.

R725.56.G76 2009

174'.957—dc22

2008040016

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INTRODUCTION

his book offers a basic overview of some central issues in bioethics from a Christian perspective. Since the early years of the church, Christians have seen it as their duty to help provide care for the sick and dying—a mission that continues to this day. But in today's world we face questions Christians in the past never had to consider:

- ▶ Is it right or wrong to remove life support from a person in a persistent vegetative state?
- ▶ What about sperm donation or buying someone else's eggs? May we use these technologies to help infertile couples have a baby?

We worry about how Christians should respond to the fact that many Americans don't have access to health care because they're members of the "working poor"—their jobs don't provide health insurance but they make too much money to be eligible for health care through Medicaid. And we wonder about our responsibility to the poor outside our country: is it our job, as Christians, to worry about other countries' health care problems?

For most of the history of the church, these issues were not matters of concern—for the simple reason that all of them are caused by changes in technology and social structures. For instance, today we can keep people alive far past the point where their hearts and lungs would have stopped beating and breathing in earlier days. But because we can, should we? Must we? We can manipulate many individual parts of the reproductive process. But is that a good thing to do? We live in a world where health care has become very expensive and very effective at the same time. But the better it gets, the less affordable it becomes for the world's poor.

As Christians we want our thinking to be guided by Scripture and by the church community, but these aren't the sorts of questions for which we can easily find answers in Scripture. Solomon's wisdom can help us with many issues in human life, but it doesn't directly address questions about the genetic testing of embryos or about the best response to the spread of drug-resistant tuberculosis. And while the thinkers of the Christian church offer centuries of wisdom, even the best offer little direct guidance on whether we in the developed world have a moral duty to provide generic versions of antiretroviral drugs (the best preventative for

HIV/AIDS infection available) to pregnant women in third world countries to prevent transmission of the virus to babies.

For many of us, our first real confrontation with bioethics issues may be at the bedside of a dying parent when we face questions about the removal of a ventilator. That's probably a time in our life when we won't be thinking too clearly! We'll be better equipped to think through some of the difficult questions raised by contemporary health care if we consider their complexity *before* we have to deal with them concretely and personally. We'll also think more clearly about the broader issues of just access to health care and how it should be distributed if we consider the wide variety of issues involved in answering such questions.

"If our own conversations with the families of the sick and dying are at all representative, what many people want when sickness threatens or death is at hand is a way to make sense of what is happening, or some reassurance that God will make it all come out right in the end. A conversation deserving of a lifetime of action and contemplation must necessarily be condensed into a few minutes, hours, or, at most, days."

—Joel Shuman and Brian Volck, Reclaiming the Body

This book is designed to help the reader begin that thinking process. It doesn't offer complete coverage of every possible bioethical issue, nor does it try to describe every possible position on these issues. The aim of this book is to cover a representative range of issues, from intensely personal issues to global, policy-level concerns, and to do so from a Christian perspective shaped by faith, by the church over the past centuries, and by ongoing debate among critically engaged Christians who work on bioethics.

In the first chapter we'll look at some of the features of a Christian approach to bioethics and compare that approach to the standard model of bioethics in contemporary health care—the Principles Model. We'll note in what way the two approaches are compatible as well as how they offer different ways of thinking about bioethics. Subsequent chapters discuss specific issues—from end of life cases to ones at the beginning such as abortion and assisted reproduction; from questions about access to health care in the United States to questions about global access to health care. We'll also consider some structural questions about the focus and direction

of health care. We'll be looking at both chronic diseases and conditions that require emergency treatment and considering the complex questions about how we as a society should respond to both of these.

This book won't answer all your questions about health care—in fact, it may leave you with more questions than when you started! What it will do is help you to recognize what sorts of ethical issues arise in health care, why they arise, and what sorts of responses are available. Because we live in a complex world, the problems of bioethics don't have easy answers. Every solution to a single problem seems to generate several other difficulties! But Scripture calls us to be wise. In the area of bioethics, a large part of wisdom is recognizing the complexities of our world so that we don't offer simplistic answers to complicated questions. It's our hope that this book will generate the kind of discussion that leads to the beginning of wisdom about bioethics.

CHRISTIANS, HEALTH CARE, AND BASIC MORAL REASONING

ila Nichols sits opposite her pastor, Charles Kim. They're in his office, a grey Michigan sky framed in the window. "Pancreatic cancer has a really low long-term survival rate," she says. "The doctors are giving me less than six months to live. I'm thinking about contacting hospice and just having low-level chemotherapy to slow the progress of the cancer. I want to skip the aggressive treatment that one of my doctors is recommending. But my friend Martha keeps telling me that I'm giving up. She says that's the same thing as suicide. What do you think?"

Pastor Kim shakes his head. "I'm so sorry to hear this, Lila. I don't think hospice is the same thing as suicide, but I'd like to talk about it with you. How can the church be there for you right now?"

"Oh, I don't want the church to know," she says emphatically. "I'll tell a few close friends, but I don't want people in church talking about me. In fact, I thought about not coming anymore. I don't want people to see me getting worse, and I don't want to be a bother. So I really don't want you to tell anyone. Like I said, I just wanted to see if you think hospice is the same as suicide. And please don't get any ideas about having people pray for me. I don't need any of that right now."

"If you don't want people to come and pray for you, I'll respect your wishes," says Pastor Kim. "But I do think you need to rethink the plan to keep this private. This is the sort of thing that should be shared with the church, and I think you'll find that you get a lot of support and love when you do."



In this chapter we'll look at a biblical framework for thinking about bioethical decisions, beginning with the centrality of healing as a sign of God's kingdom in the world. Scripture is full of stories of healing: from the healing miracles so central to Jesus' ministry, to Elisha's healing of

his patron's son, to the use of healing as a description of God's love in the prophets.

Clearly spiritual health is important, but we should never lose sight of the fact that Scripture draws close connections between our physical and spiritual health. The brokenness of the fall leads to disease and death, and the redemption achieved through Jesus' death brings both spiritual and physical healing—and ultimately, the overcoming of death altogether. Given that emphasis, it makes sense to ask how Christians should approach issues of health and sickness, of medicine and faith healing, and of new technologies and the timeless recognition that we humans do get sick and die.

THE CHURCH AS COMMUNITY

One of the most important features of our lives as Christians is the fact that we don't make life and death decisions all by ourselves. We are connected to God and to each other. That's why Christian thinking about medicine and bioethics differs from the standard models of bioethics taught in medical schools across the country. Those models emphasize individual autonomy and protecting the patient's right to make decisions—both very important issues. But their focus is on people as isolated individuals, not as members of a community.

Two sets of considerations, then, structure our thought as Christians about controversial and difficult issues in bioethics. The first deals with how we make decisions as members of the body of Christ. How does that help shape the decisions we make and the way we make them?

The second relates to the way the church as a whole should respond to bioethical issues. What we choose to do and say as the body of Christ provides an image of God to the world. How can we faithfully reflect who God is to those around us? Can our response to bioethical issues make visible the good news of God's love and redemption? These questions need to shape our reasoning about bioethics so that our decisions and actions reflect Christ in our lives.

Shaped by these two sets of considerations, the central focus of this book is not so much on individual decision-making in standard bioethics mode, but rather on how the Christian community can respond faithfully to the health care issues and needs around us.

THE STORIES OF SCRIPTURE SHAPE OUR LIVES

One of the first things we need to recognize is that a community's identity is shaped by stories. This is obviously true for the church—a community

that historically has found its identity in the stories of Scripture. The stories of Scripture tell us who we are and where we come from. They tell us about the goals of our actions and our lives. For Christians, the most important story has three parts: the story of God's creation of the world; the human fall from a right relationship with God into one marked by conflict, separation, and sin; and God's redemption of right relationships through the life, death, and resurrection of Jesus. It's the story of a future we look forward to—a world made whole again by God's grace.

"These stories are not situated within the world: instead, for the Christian, the world is situated within these stories."

—John Milbank (Quoted in Joel Shuman, Heal Thyself)

This overarching structure allows us to see that the world God created is good and that it was made for a purpose—for God's enjoyment and for our flourishing. In the health care context, we see this basic goodness of creation in any number of ways:

- ▶ in the almost miraculous way bodies can heal themselves, given half a chance
- ▶ in the way humans develop from embryos into babies, then into adults who grow and flourish physically and emotionally
- ▶ in the ways people reach out to each other to help, to care, and to express love
- ▶ in the wonderful capacity medicine has to heal and to save lives that would otherwise be lost

People who work in the field of health care see all sorts of wonderful structures and events that we can celebrate as the good gifts of God.

But life is not all good. We live in a world that is full of broken relationships, sinful choices, tragic illnesses, and death. This too is part of the story Scripture tells. Things are not all right with the world, and we can see this in the context of medicine:

- ▶ People get sick and sometimes there's no cure.
- ▶ People hurt each other deliberately and by negligence; health care workers have to care for the broken bodies and suffering minds of those damaged by others.

- ▶ People die despite our best efforts; in some really hard cases people die *because* of what health care workers have done to them.
- ▶ Even when medicine can offer a cure, it doesn't always restore a person to complete health. Medicine that slows the progress of a disease can have side effects that make a person miserable. Surgery to correct one condition can generate other problems that can't be fixed.

Christians experience both aspects of the world: its basic goodness and its corruption by sin. But we aren't just passive bystanders. God created us to be active participants in the world, engaging in the unfolding story that God is writing. Our job is to live in ways that reflect our hope in the good future God is bringing about. This gives us a context for making sense of what happens to us and for figuring out how to live as the body of Christ in the world.

"Reading Scripture trains us to see the religious significance of events, to read the signs of the times in the things that are happening about us, and to locate events and circumstances—as well as our selves—in a story of God's power and grace."

-Allen Verhey, Reading the Bible in the Strange World of Medicine

Christian thinkers and writers, including ethicist Allen Verhey, have argued that one of our central tasks as the body of Christ is to become the sort of people and the sort of community that represent God to the world. The good news of God's love needs to be visible in us. That's much easier said than done: it isn't hard to *talk* about being a loving community, but anyone who's been a member of a church for very long knows that actually *doing* it can seem pretty much impossible on the bad days, and tough even on good ones.

Developing the character traits we need to live together as a loving community doesn't happen overnight. If I want to be a gentle, generous, honest person, I have to spend years practicing those characteristics until they become so ingrained in me that it would be difficult to act dishonestly or selfishly. That takes hard work and extensive practice! And few of us have the discipline on our own to really work at it. (After all, working on character fitness is a good deal harder than working on physical fitness, and most of us can't even do the latter!) That's where community

comes in. The church provides us with a group of people working on the same issues. Together we can schedule times to do volunteer work and meet together to talk about issues we're struggling with. Together we can find ways to practice the virtues we should exhibit to the world.

We recognize a person's character by her or his actions, but also by how that person resolves problems. Communities are the same. We recognize the character of a community by how it identifies, speaks to, and resolves problems. A church that says it follows Jesus but resorts to character attacks and underhanded dealings when confronted with conflict reflects badly on Jesus' name. Our actions as the body of Christ leave a stronger impression in the world than the words we use or the sermons we preach.

When the church community embodies God's love and grace to its members, it has the potential to be a powerful force in society. In the context of bioethics, for example, a church community that reaches out to its members struggling with chronic illness, supports them, loves them, and keeps them enfolded in the community is a church that can speak credibly to the world about the needs of those who deal with chronic illness.

SOCIETAL STRUCTURES AND REDEMPTION

Psychologist Mary Stewart Van Leeuwen notes that Scripture uses the language of "principalities and powers" when speaking about the social structures of human life. The "powers" are social forces that shape and even determine the ways we can act in the world. They are so big and so entrenched that no single individual can simply decide to set them aside. We live in a world structured by a global economic system, for example, and whether we like it or not, that fact shapes our lives and our options. Other powers that shape us include family structures, economic structures, political structures, education systems, and (most centrally for our purposes) medicine.

Sometimes these powers take on a life of their own, like Frankenstein's monster. When they claim to determine the whole meaning of human life, they become idols—they stand in the place of God. Medicine, for example, is a powerful and complex social structure. People turn to medicine for health, safety, and meaning in an uncertain world.

- ▶ For those who are sick and dying, medicine offers healing and comfort.
- ▶ For those who are dissatisfied with their lives, medicine offers diets and cosmetic surgery.

- ▶ For those who feel their lives have no meaning, medicine offers antidepressants and mood enhancers.
- ▶ These can all be good things. But none of them are "the pearl of great price" Jesus refers to in Matthew 13:46 (KJV), and if we start thinking they are, we're in trouble.

"The alternative to the idolatry that is bondage to the powers is the proper worship of God. By *worship* we mean . . . the entire orientation of lives that have been shaped by the repeated retelling and reenactment of the Christian story on Sunday mornings."

—Joel Shuman and Brian Volck, Reclaiming the Body

In the abstract, of course, it is relatively easy to see that medicine should not be the central focus of our lives. But in the midst of a medical crisis—when our child is diagnosed with cancer or when we're struggling with infertility—it can become very easy to find all our hopes and dreams resting on the outcome of the next diagnostic test or the latest technological procedure. When this happens, not only are we placing our hope in the wrong place, we are placing it in a system that cannot hope to truly satisfy. Medicine is a good thing, but it cannot stave off death forever or repair broken lives. And like other idols, it will betray us.

Many of us, in fact, have experienced this sense of betrayal to some degree. A hip replacement, for example, may offer the hope of new life and perfect function. But though we can expect a good deal of improvement after a hip replacement, we are unlikely to ever feel "new" again. And no matter how much we turn to medicine for relief of the "symptoms" of aging by undergoing plastic surgery, vitamin therapy, Botox injections, or hormone replacement, our bodies continue to age.

It's not hard to see that medicine is a power in our lives—a force that appears to offer meaning, wholeness, and healing to us in almost magical ways. So we react with anger and bitterness when medicine turns out to be a fallible, human practice. After all, the mistakes and limitations of medicine are lived out in our very flesh. When my hip replacement doesn't work well, it's my body that aches every day. When a surgeon makes a mistake, I'm the one forced to wear a colostomy baq.

Many of the lawsuits brought against doctors are filed by those who feel betrayed. These people thought medicine could solve their problems, but it didn't. No one wants to be in that small percentage of people who don't survive general anesthesia, but the reality is that there is a risk, and some people will die. We have an image of medicine as all-powerful, offering solutions for the problems that we worry about. The suspicion and hatred people sometimes feel toward doctors and medicine as a whole is the dark side of the idolatry of medicine.

Christians have an alternative view of the power of medicine. We can appreciate its tremendous power and its resources for good. But we know that medicine is not a god who will save us if we sacrifice sufficient money and resources in its name. And if we pursue immortality through medicine, we will fail at the tasks that we should be pursuing: living the lives God has called us to and serving the needs of others. Ultimately we recognize that medicine is an important part of human life, one that should be situated within God's larger plan as one important good among many—never the ultimate good.

THE LANGUAGE OF BIOETHICS: PRINCIPLES-BASED REASONING

So far we've talked about how the Christian community might understand its own relationship to the practices of modern medicine. But when people find themselves dealing with the health care system, it isn't enough to be able to frame medicine within a Christian worldview. We also need to be able to translate our values and beliefs into language that makes sense to doctors, nurses, and sometimes administrators who may not have much concern for or understanding of Christian perspectives.

Contemporary bioethics is fundamentally shaped by *principles-based* reasoning, a method developed by James Childress and Tom Beauchamp in their book, *Principles of Biomedical Ethics*. The four principles they developed offer a common language for medical professionals and others to talk about ethics and resolve conflicts:

- autonomy (respect the patient's right to make decisions)
- beneficence (help others)
- ▶ nonmaleficence (do no harm)
- justice (make sure burdens and benefits are fairly distributed)

Autonomy refers to the patient's right to make decisions about her or his own care. It includes the right to be informed about available treatments, the nature of any proposed interventions, and the side effects and probable outcomes of those interventions.

Beneficence identifies the central medical goal of helping others. Nonmaleficence refers to the moral duty to refrain from doing harm.

Sometimes it is hard to distinguish between benefiting others and refraining from harm, but they do differ. Doctors may focus so single-mindedly on trying to cure a patient, for example, that they lose sight of the harm their techniques may cause. Separating beneficence and nonmaleficence reminds us to balance trying to help and avoiding harm.

Finally, the principle of *justice* reminds us that health care must be available to those who need it, whether in individual cases, as when many people want access to a particularly scarce resource (as often happens in organ donation) or on a broader scale, such as the huge number of people without access to basic health care in some countries, including the United States.

Being able to refer to these principles provides a helpful context for discussing health care among people who may have lots of different ideas about ethics and moral responsibilities. Because they work pretty well in that capacity, they've become standard in many discussions of bioethics.

But as is always the case, the more general our principles are, the harder it is to apply them in specific situations. For example, when debating whether or not it is acceptable to remove a ventilator from someone in a persistent vegetative state, one person may say that it would be a benefit to keep the patient breathing (a fairly obvious benefit!); another may argue that extending the dying process over a long period of time actually harms the patient. There's no easy way to resolve such conflict if the principles themselves are our only resource.

"A persistent vegetative state, which sometimes follows a coma, refers to a condition in which individuals have lost cognitive neurological function and awareness of the environment but retain noncognitive function and a preserved sleep-wake cycle.

"It is sometimes described as when a person is technically alive, but his/her brain is dead. However, that description is not completely accurate. In persistent vegetative state, the individual loses the higher cerebral powers of the brain, but the functions of the brainstem, such as respiration (breathing) and circulation, remain relatively intact. Spontaneous movements may occur and the eyes may open in response to external stimuli, but the patient does not speak or obey commands. Patients in a vegetative state may appear somewhat normal. They may occasionally grimace, cry, or laugh."

—Healthlink, Medical College of Wisconsin

A Christian perspective offers other resources to draw from. Situating the bioethical principles we've described within the context of Scripture and the Christian tradition gives us a rich source of material for thinking about bioethics.

1. Autonomy

Let's start with the principle of autonomy, which reminds us that the related concepts of freedom and responsibility are crucial components of human life. Because I can choose from a variety of options, I am also responsible for what I choose. If I have no options or am unable to choose, I can't (realistically) be held responsible for what happens.

Our culture tends to equate diminished health and vigor with diminished humanity. Friends of mine who use wheelchairs, for example, recount stories of people looking past them as if they can't speak. And the elderly are routinely treated as incompetent or invisible. As Christians who recognize the image of God in all people, we need to counter this cultural bias by respecting the autonomy of everyone, healthy or sick, old or young, vulnerable or strong. But as Allen Verhey reminds us, autonomy doesn't mean leaving people alone to make whatever decision they want. Christians know that true autonomy is best exercised in community, in conversation with those who know and love us best.

2. Beneficence

The second principle reminds us that we have a duty to help others. Both the Old and New Testaments are so full of God's commands to feed the hungry and care for the widowed, the orphaned, and the foreigner that it is impossible not to see connections between beneficence and a Christian worldview.

The Christian call to protect and help the weak and vulnerable in society forms an important background to medical history. The early church created communities devoted to the care of the sick and the elderly. Hospitals were originally shelters created for the sick and weary on pilgrimages. The church community frequently made houses of refuge and care for the sick a central part of their ministry; even today the names of many hospitals across North America point to their historical connection to one or another Christian community.

This historical perspective suggests one significant difference from the general principle of beneficence. While beneficence may sometimes be a matter of one individual helping another (as in the parable of the Good Samaritan), the church historically has seen this as a collective duty. The

needs of the poor and vulnerable are likely to require structural solutions: institutions, funding, specialized training, and long-term commitments. As Christians we are called to help in ways that make a real difference.

From a Christian perspective, the principle of beneficence also needs to address the tendency to focus only on physical life and health. As important as both of these are, they need to be set within the broader context of the spiritual and social aspects of human life. A person is never merely a body to be fixed and sent on its way but is rather someone who lives in relation to God and to others.

3. Nonmaleficence

The third principle cautions us to avoid as much as possible the harm that can be caused by the practice of medicine. Again, Christians have a particular perspective on this principle. Most folks recognize that when medicine causes more physical problems than it solves it is bad medicine. But Christians are also aware, as we noted earlier, of the temptation to put our whole trust and faith in the practice of medicine, to think that doctors can fix all that is broken in our lives.

4. Justice

This final principle naturally resonates with Christians. Scripture is full of commands to do justice, especially when those who have power use their position to manipulate or exploit those who are weaker. In the field of health care, this sort of exploitation can take any number of forms. Poorer countries, for example, have recently struggled with forced "donations" of kidneys. These organs are sold to wealthy Westerners willing to pay a premium price for an organ that is not readily available in North America or Europe. Other injustices are more systemic: because of the huge disparities in wealth between poor nations and wealthier ones, only the wealthy have access to premium health care, while the poorest have minimal or no health care. Christians bring to their discussion about justice the conviction that all humans have value, not just those who are wealthy.

When we as Christians find ourselves maneuvering through the health care system, the four principles we've discussed give us a language that caregivers will understand. But we need to flesh out these basic ideas with the broader perspective our faith makes available.

CONCLUSION

Christians approach bioethics from a number of different viewpoints. One of the things this book aims to do is look at how different Christians have

approached various bioethical issues, what conclusions they have reached, and why. We will not offer quick or simplistic solutions—after all, most bioethical issues are debated precisely because they are complicated and difficult and because they represent areas where there are deep conflicts of interest between individuals or groups. Responsible Christian freedom requires us to think for ourselves when discussing the issues we'll cover in this book.

At the same time, Christians need to recognize God's guidance as we think through difficult issues. Our stories are situated in the context of Scripture. As children of God, we are called to be light and salt to the world. We're called to live out God's love and compassion for other people and the rest of creation. Further, we don't make decisions as isolated individuals. We live as members of God's family, a community into which we have been baptized. Our church community is both immediate (the folks we see in church) and very far away (Christians living on the other side of the world, often in very difficult situations). The church is a community with a long history and with enormous wisdom accumulated through ages of thinking about what it means to be a follower of Christ.

"To speak properly of health we need to describe the place where the personal and the communal intersect. The freedom that is health cannot be found in solitude: it is a freedom found when we humans learn to cooperate . . . to reach a common goal."

—Alastair V. Campbell, Health as Liberation

In our discussion about bioethics we'll try to listen carefully to what other Christians say and to what modern medicine can tell us. We'll also think for ourselves. We'll consider alternative viewpoints and the reasons that Christians might disagree about some of these issues. Finally, we'll try to adopt an attitude of gentleness, humility, and respect for those who may not agree with us. Scripture commands us to seek wisdom; it also reminds us that for now we see only through a glass darkly. We'll try to remember that tension as we think about the various bioethical issues of our day.

Questions for Reflection and Discussion

- 1. How would you counsel Lila if you were Pastor Kim in the scenario at the beginning of the chapter? What other issues, if any, should be explored?
- 2. Review and evaluate the four principles widely used in discussing bioethics. How does our membership in the family of God add to or shape the discussion?
- 3. This chapter uses the language of "principalities and powers" to talk about social structures such as health care. How does the power of medicine and health care tempt us to idolatry? How can a Christian perspective help us to see medicine in its proper place?
- 4. Healing is central to the ways Scripture portrays the kingdom of God. How can churches build a concern for healing into their ministries?

For Further Reading

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