



Delight in Creation

Scientists Share Their Work with the Church

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3 Bioethics

by Hessel Bouma III

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As graduate students in human genetics at the University of Texas Medical Branch, we participated in weekly genetic grand rounds to put a face on the genetic conditions and diseases we were studying. In about the third week of my first year, the physician in charge scurried in, a few minutes late, stethoscope around his neck and a lantern flashlight bulging out of his white coat pocket. How odd! Excitedly, he beckoned us to follow him. We wound our way through the complex hospital corridors, up to the neonatal intensive care ward. As we made our way past newborns connected to all sorts of technology, we headed to the back corner of the ward, farthest from the nurses' station, to a bassinet devoid of technology—and a newborn with a grossly enlarged head.

Tenderly, the pediatrician lifted the infant, cradling it in one arm with his hand supporting its oversized head while reaching with his other hand for the lantern flashlight. He flicked the light on and held it to the underside of the infant's head. We gasped! Someone pointed to the ceiling—in turning away from the sight of the infant's illuminated head, the student had noticed that the flashlight beam had passed through the infant's head, scarcely impeded, and was shining as a diffuse cone on the ceiling. We looked back at the infant. The infant's head was illumined like an alien from outer space. On closer examination, we could see some rudimentary bones in the face and edges of the skull, and a few blood vessels. But clearly, there were no opaque masses of brain in this infant's head to impede the light.

The physician explained. This anencephalic infant was born that morning. It was missing four-fifths of its brain, possessing only a brainstem that controls respiration, heartbeat, and digestion. Approximately one-third die before birth and one-third die at or shortly after birth, but one-third survive and healthcare practitioners and parents must make difficult decisions about whether to treat these infants with all sorts of technology or allow them to die. He presented the biomedical facts and said that anencephaly occurs in about one in five hundred newborns.

It was an immensely disorienting moment. Time seemed to both rush by and stand still. To this day, I have no idea how long we stood there. We peppered the physician with our curiosity questions. I recall thinking, "Little in my Christian education has prepared me for a moment

like this." I also wondered, "Without the portions of a brain responsible for consciousness, thinking and feeling, is an anencephalic newborn a person?"

At one point, I asked if the infant was a boy or a girl. The physician acted a bit peeved, as if the answer didn't matter, but he peered into the diaper and announced, "It's a girl." Despite now knowing the sex of the newborn, he continued for the duration of our grand rounds to refer to her as "it." Was he consciously or subconsciously acknowledging that without higher cortical functioning, biological sex and genital sex doesn't and cannot mean gender?

In ensuing days and weeks, I had several occasions to speak with the other graduate students about their further thoughts on the newborn girl with anencephaly. I discovered that my Christian liberal arts education had probably prepared me better to think about the issues of what makes a person a person and how we ought to care for a newborn with anencephaly than my classmates who had attended secular institutions and focused on the sciences while avoiding or minimizing philosophy. Only later, when my wife and I became parents, did I reconsider this anencephalic girl from the parents' perspectives. Had they known in advance that their daughter would be anencephalic? As parents, how do you tell your family and friends about your newborn, and why you made a very difficult decision not to initiate technological interventions? How should we as Christians respond to parents with an anencephalic newborn? Should we baptize her—even if she is stillborn?

What Is Bioethics?

Bioethics (or biomedical ethics or medical ethics) is the fascinating study of moral dilemmas that occur as a consequence of new developments in biology and medicine. Historically, many of the Greek philosophers, Jewish rabbis, and Christian church fathers addressed various moral dilemmas of their times. Must you always tell the truth? May you withhold bad news from a dying person? Modern bioethics arose in the 1960s and 1970s as technology and medicine developed new abilities to sustain and improve the quality of life. These included the developments of kidney

dialysis, respirators, heart by-pass machines, organ transplants, artificial hearts, genetic engineering, gene therapy, birth control, and a veritable arsenal of assisted reproductive technologies.

Bioethicists are persons with an interest and expertise in thinking through the moral dilemmas of biology and medicine. Most bioethicists are first and foremost philosophers, theologians, biologists, or healthcare practitioners (usually physicians or nurses), though some also come from the ranks of sociology or the law. Our work is interdisciplinary, spanning the fields of biology, medicine, law, sociology, history, philosophy, and theology. We enjoy working thoughtfully and carefully through dilemmas, considering options, alternative points of view, and the values of the persons involved. Many bioethicists, particularly if agnostic or atheistic, are predominantly humanists, committed to the well-being of humanity and usually sensitive to the religious dimensions of ethical dilemmas. Many other ethicists have religious underpinnings to their work. Jewish bioethicists apply the Talmud and rich tradition of rabbinic teachings to new dilemmas. Numerous bioethicists operate within various Protestant denominations or religious sects, seeking to apply scripture, their confessions, traditions, and experiences. Catholic bioethicists, many from the Jesuit tradition, were instrumental in articulating today's widely held ethical principles of *autonomy*, *non-maleficence* ("do no harm"), *beneficence* ("do good"), and *justice*; they did so out of their Christian convictions and the application of scripture. The U.S. Conference of Catholic Bishops and some papal teachings specifically address bioethical issues including abortion, birth control, physician-assisted suicide, voluntary euthanasia, and social justice.

Bioethics impacts our practice of medicine. From the ethical principle of autonomy comes our respect for privacy and confidentiality, and our practice of informed consent. A competent person should be the one to choose what healthcare practitioners or researchers may or may not do to them. A patient may choose to withhold or withdraw medical treatments, even if they might be deemed life-saving. If a patient isn't competent, bioethicists and the courts have sought to establish who is in the best position to decide for the incompetent patient. And if persons anticipate losing their competency in an accident or to mental illness or

dementia, they may designate a surrogate decision-maker and write an Advance Directive to guide their loved ones and healthcare practitioners in their care. Sometimes our societal emphasis on individual autonomy seems to run amok, such as with Nadya Suleman, a single mother of six children who chose to undergo an additional transfer of frozen embryos that resulted in the births of octuplets. Balancing the ethical principles of non-maleficence and beneficence helps patients, their families, and their healthcare providers weigh the harms versus benefits of a medical intervention. The ethical principle of justice—distributive justice—has assisted us in developing an elaborate system for the distribution of scarce organs to patients in need (see the United Network for Organ Sharing at <http://www.unos.org> for details). It is the principle of justice that haunts the current debates on the reform of the U.S. healthcare system as we realize more than 50 million citizens lack access to basic healthcare.

Broad, new bioethical issues often arise quite suddenly, and it may take years to settle on appropriate solutions based upon various moral vantage points. For example, Ian Wilmut's cloning of Dolly the sheep opened the door to the possibility of human cloning. Just because we can, should we? The discovery of human embryonic stem cells rekindled the debate about the moral status of frozen embryos—are they frozen persons, entitled to a right to life, or something of lesser value, that might be used for others? Several horribly disfigured persons have undergone full facial transplants. Does a facial transplant affect a person's identity? Often, scientific developments precede moral guidelines, as in the two latter issues above. To help anticipate and bridge the gap between science and morality, institutions involved in human experimentation are required to have institutional review boards and ethics committees to review experimental protocols and give approval before new methods and drugs are tried on people. In addition, Presidents Jimmy Carter, Bill Clinton, and George W. Bush formed national advisory committees on bioethical issues to help identify and frame bioethical issues for the country, politics, and the law.

At a personal level, bioethical issues also may arise quite suddenly and threaten to overwhelm us. Consider the following examples:

- A young couple learns their long-sought pregnancy puts the mother's life at risk. May they terminate this pregnancy?
- A child is diagnosed with stage-four brain cancer. Must they aggressively pursue some combination of surgery, radiation, and chemotherapy in the face of a very grim prognosis, or may they seek to make their child as comfortable as possible, cherishing their remaining days together?
- A young teenager is violently raped by a stranger. May she use Plan B, an emergency contraceptive? May Christian healthcare practitioners offer Plan B to her as an option?
- A serious accident leaves a loved one in a coma, on a ventilator, with diminishing signs of brain activity. Within hours, healthcare practitioners begin talking to the family about the possibility of turning off the ventilator to allow their loved one to die peacefully...and possibly harvesting his organs to save or improve the quality of the lives of others. Should they?
- A couple in their late thirties with a five-year-old child and two-year-old twins, seek pastoral advice. Unbeknownst to anyone but their closest confidants, this couple's children were conceived through in vitro fertilization (IVF). When they initially underwent the IVF procedure, they were so longing for children, they had quickly consented to the specialist's advice to fertilize the twelve eggs that had been harvested. The couple has concluded that their hands are now full raising their three children and it would be irresponsible for them to have more children. But they have five frozen embryos stored at the fertility clinic. What should they do with these frozen embryos?
- Grandpa was diagnosed with Alzheimer's disease years ago, and it's been three years since he recognized Grandma or any of his children or grandchildren. Lately, he has become combative, resulting in his transfer to a special facility. Healthcare practitioners initiate conversations with Grandma and his children about possibly using physical or chemical restraints to control him. They also suggest the family consider authorizing a "do not resuscitate" order should his heart stop, and possibly

withholding antibiotics should he develop pneumonia, allowing him to die fairly peacefully in his sleep. As Grandpa and Grandma's pastor, how would you advise them?

Many people begin to wrestle with bioethical issues with healthcare practitioners who may not share their moral values. Ideally, for people of Christian faith, their pastor should be among the first people outside of their immediate families and healthcare practitioners to whom they turn for advice and comfort. Some parishioners are reluctant to do so, fearing their pastor's judgment or doubting their pastor's ability to be of much help. Other parishioners trust their pastor to be compassionate and caring, honoring confidentiality while walking alongside them through difficult decisions, and helping them to discern significant moral and religious values while resisting any inclination to tell them what they should do.

When bioethical dilemmas occur within a healthcare setting, most hospitals have a bioethics committee available to assist healthcare practitioners, patients, and their families in considering their options. The committees are typically composed of community members and healthcare practitioners, including doctors, nurses, social workers, bioethicists, and chaplains familiar with various faith traditions. In most circumstances, patients are welcome to bring their pastor to a meeting of the bioethics committee when their case is being discussed. Pastors can play a vital role in helping identify the patient's moral and religious values in the meeting or simply in listening so as to learn and speak further with the patient later.

Biblical and Theological Context

There are numerous potential intersections between biology, medicine, and bioethics on the one hand and scripture, theology, tradition, reason, and experience on the other. For Christians, the realities and truths of biology and medicine are part of God's general revelation, discovered through processes of experimentation. They are reflections of truth that point us to God the Creator and Sustainer. But because these are human endeavors, they are prone to misinterpretations and errors. Our theology is based upon special revelation—the scriptures—and truths that also

reveal God to us. But theology is also a human endeavor, similarly prone to misinterpretations and errors. In bioethics, we seek to understand both special and general revelation, and God's purpose and will for us in difficult moral dilemmas.

Bioethics may be perceived as involving the three central motifs of the Christian faith: the creation, the fall and redemption. In the motif of creation, we understand that God created all things good and established the moral order. As part of that moral order, humans have a special role (the care of God's creation) and a special moral status (bearers of God's image). What does it mean that humans and humans alone are created in the image of God? What is the moral status of the unborn—unimplanted embryos, embryos and fetuses? How should we understand the cultural mandate to be fruitful and multiply?

In the motif of the fall, we understand that through humankind, evil entered the world. Evil is real and it affects everything. Human health and flourishing are diminished by sickness, suffering, and death. What are the relationships between sin, sickness, and suffering? Sometimes there are direct links, as in the case of someone who abuses alcohol, develops liver cirrhosis, and is likely to die without a liver transplant. But sometimes there are no direct links as Jesus tells his disciples (John 9:1-12). Many Christians experiencing an accident, disability, or ill health will be led to ask, "If God is good and all-powerful, why am I suffering?" But God did not allow evil to occur without offering hope through the promise of salvation.

The motif of redemption encompasses Jesus' life, suffering, death of atonement, and resurrection. In Jesus' life, we see an extraordinary emphasis upon caring, healing, and teaching. In Christ's resurrection, we observe his victory over death, but must acknowledge the "not yet" character of this victory. The victory has been achieved, but all of us will still die. The victory comes to us in the new heaven and the new earth, where death, mourning, crying, and pain will be no more (Rev. 21:4). A corollary to the motif of redemption is *restoration*. For Christians engaged in biology, medicine, and bioethics, there is a vocational calling toward fundamental understandings of how things are and how we might work to restore them toward God's original intent in the creation.

When Christians hear about a bioethics case, there is usually an initial natural curiosity about the biology and medicine involved. How could Nadya Suhlman conceive and give birth to octuplets? What happened to Terri Schiavo that she lapsed into a persistent vegetative state? How do we *know* she wasn't seeing or feeling? What would lead someone to seek a face transplant, and after a face transplant, will the person's face look like her original face, or like the face of the donor? Questions quickly follow about whether the situation was preventable, whether it was the result of bad choices, and what options there are for resolving the case. Most people have a moral intuition that certain courses of action are distinctly preferable to others, and can articulate reasons for their position. On a few issues such as abortion or physician-assisted suicide, some Christians may have such deep convictions that they cannot perceive any bioethical dilemma. In most instances, however, Christians are willing, if not eager, to learn of different viewpoints and to consider various options. What options are there? What are the relevant values and ethical principles behind the various options?

When asked difficult bioethical questions from students or fellow parishioners, I try to gauge their positions and the reasons for their positions, and then engage them in the process of considering alternatives. A young wife, excited about her first pregnancy, develops intense abdominal pains accompanied by vaginal bleeding. Her physician concludes she has an ectopic pregnancy—the embryo has implanted somewhere other than in the uterus. Her life is in serious jeopardy. May she terminate the pregnancy? Suppose she reluctantly decides to terminate the pregnancy and her husband disagrees? Some Christians, unalterably opposed to any and all abortions, may insist that pregnancy termination is not an option, perhaps even suggesting that the ectopic pregnancy is part of God's will, and God may be calling her to sacrifice her life as a testimony to how evil abortions are and to leave open the possibility of a miracle by God for whom nothing is impossible. On the other hand, Christians who are opposed to abortion in almost all circumstances may allow that, when a mother's life is genuinely threatened, it is permissible to terminate a pregnancy. Some may consider it a type of justifiable homicide or self-defense, viewing the embryo as an aggressor who is threatening the mother's life. They do not view this as

usurping God's sovereignty over unborn life. They are deeply saddened by the loss of embryonic life, but think of the pregnancy termination as a responsible use of technology with which God has entrusted us to restore the health and flourishing of the mother, without which the mother is likely to die.

From a theological standpoint, I would caution Christians against thinking of God as the author of evil. An ectopic pregnancy is a testimony to the reality of evil in the world, but that evil arose through the choice of humankind. God allows ectopic pregnancies to occur, but does not will them. From a biomedical perspective, I would ponder with Christians the evidence that three-fourths of fertilized human eggs naturally fail to thrive through the gestational process, which is a staggering loss. For each infant welcomed into our churches, three embryos failed to survive. How does God know these embryos? I do not have a simple answer. But I think there is some comfort for the couple who experiences infertility, a miscarriage, or decides to terminate an ectopic pregnancy in realizing that virtually all couples experience the deaths of embryos, even if they occur so early in gestation that they are not aware of them. There ought to be a sense of shared suffering and loss, uncertainty about how God and we should know them, and a compassionate effort to understand and support persons experiencing these tragic circumstances.

Advice for Pastoral Care

When faced with bioethical situations involving parishioners, pastors and others entrusted with pastoral care should listen very carefully. It is an honor and privilege to have people share some of their most vulnerable moments and deepest concerns with you. Consider the following principles, gleaned from my experience as a Christian in the field of bioethics:

- Assure them of your love, concern, and willingness to assist. Can you promise to be supportive of them in their decisions, even if their decision might ultimately be different from what you would recommend? Can you offer the support of your elders and

congregation, too? Don't offer that support unless you're quite sure of it.

- Learn as much as you can about the biomedical facts. If you are blessed to have some healthcare practitioners in your congregation or to know other Christian healthcare practitioners, ask them to help you understand the biology, medicine, and ethics of situations. Try to discern the certainty and uncertainty of the diagnosis and prognosis.
- Carefully offer tempered, realistic hope. Pray again and again with them, both for them and for yourself that you might discern God's will.
- Ask what details, if any, you might share with the congregation. Honor their wishes.
- Avoid being judgmental.
- Avoid platitudes. For example, avoid saying, "God must have loved you so much he sent you _____," or "God won't send you anything you cannot bear."
- Be very careful trying to make conversation by comparing this situation to another situation with which you've dealt. Each situation is unique.

Pastors and churches can share in biology, medicine, and bioethics in a variety of ways. In celebrating the creation motif, the church grounds, sanctuary, classrooms, bulletins, and newsletters can be adorned with visual reminders of the goodness of God's creation—through flower and tree landscaping, floral bouquets, and nature artwork. Observing the ravages of the fall and our pursuit of restoration, the congregation as a church community can work toward being deeply caring and compassionate, encouraging parishioners to share their burdens, including health concerns. Such sharing is likely to occur fairly slowly and only if peoples' vulnerabilities are minimized and exceeded by the experience of true caring through prayer and other expressions of love, concern, and support. Pastors and elders have a special role to play in dealing with difficult bioethical issues, supporting individuals while preserving privacy and confidentiality. Congregational prayers in worship or meetings of church groups can be

opportunities to model how to petition God for healing and comfort, to express gratitude for restoration of health and well-being, to accept diminishing health and possibly dying, and both to grieve and celebrate the deaths of God's children. Adult church education programs can feature presentations of Christian perspectives on difficult bioethical issues like birth control, assisted reproductive technologies, cloning, human stem cells, Advance Directives, hospice care, organ transplantation, withholding and withdrawing medical treatments, and so on.

Becoming a Biologist and Bioethicist

Finally, I'll offer a few comments about my own calling to biology and bioethics. I grew up in a Christian family that appreciated both science and the Christian faith. I enjoyed chemistry and physics classes in high school, and as a student at Calvin College, I became fascinated by the study of life in all of its biological complexities. I was significantly influenced by many professors in my science courses and in my religion and philosophy courses who kept me thinking about science and my Christian faith. Upon graduation, I pursued my doctorate in human genetics, followed by post-doctoral research in biochemistry. In these settings, I found that many of my fellow students and professors had been raised in the Christian faith, but all too many had felt compelled to choose between being a Christian or doing science. The integration of my Christian faith with my research and science interests struck many as a paradox, but provided a means of talking openly about my faith. During my post-doctoral years, while my research proceeded reasonably well, I became discontented with the enormous time I spent focusing on the minutiae of research. Sometimes days or weeks of work would be made or broken by what happened in a few test tubes. While my wife and several friends with science interests at church understood, I felt less and less settled on a vocation as a research scientist.

While I was becoming dissatisfied with laboratory science, I continued to be involved in my local church and served on the boards of several Christian organizations. These activities led me to serving on a denominational committee with Dr. Henry Stob, professor of moral

theology at Calvin Theological Seminary. Often when the committee met and we had a break for lunch or supper, Henry peppered me with questions about my science research, the latest breakthroughs in medicine, and ethical issues. I felt God leading me in a new direction. On several occasions, he privately urged me to think about teaching at Calvin College, and a year later I accepted a position there.

Calvin College has given me a wonderful setting in which to explore my interests in biology, medicine, and bioethics. It's exciting to hear about new scientific breakthroughs and to contemplate the ethical issues these discoveries raise. God has affirmed my calling by giving me many opportunities to speak to students, church groups, and professional medical societies; I enjoy capturing the attention of my audience and getting them to think with me through the difficult moral and religious issues of bioethics. I have had the opportunity to serve on several bioethics committees at local hospitals and on the board of Hospice of Michigan. With my students, even those not majoring in science, I frequently explore Christian perspectives on moral issues in human biology.

In my scholarly work, I am studying the biomedical and ethical issues associated with persons who are identified as intersexed due to disorders of sexual development. At birth, the sex of some newborns cannot be determined by simple observation of the external genitalia, or the identification turns out to be incorrect. Much of our identity is tied up in our sex, gender, and name, and the bioethical crises precipitated by these disorders of sexual development are significant. Until recently, parents and healthcare practitioners felt compelled to try to fix the problem as quickly as possible, either through sex assignment surgery or sex hormone interventions. Growing evidence suggests that at least some of these infants were seriously harmed by these interventions, occasionally assigned a sex and gender that later did not comport with their psychological identification of sex and gender. Imagine the challenging questions young parents might ask if their newborn has ambiguous genitals. How would one announce this birth from the pulpit or in the church bulletin? What would you advise the parents to tell their families and friends?

My work impacts my faith, and my faith impacts my scholarly work. At the most basic level, I find much in biology and medicine to inspire an

awe and wonderment in God's creative handiwork. Life is so complex, even in some of the simplest organisms, that it seems to shout forth testimony to the Creator. It's awe-inspiring and celebratory, an extension of the psalmists' delight. At a higher level, my understanding of the creation order and cultural commission in Genesis 1 provides a significant framework for approaching issues in both environmental ethics and biomedical ethics. It lays forth humans as uniquely created in the image of God, granting us a special moral status, but also charging us with a responsibility to care for God's creation.

Biology and medicine may also inspire celebratory worship when their applications are successful. Rarely is the extent of one's gratitude surpassed as when unlikely healing occurs. Imagine a child at death's door responding beyond our wildest expectations to a bone marrow transplant of last resort, a stroke victim regaining the ability to talk through endless hours of speech therapy, or a young father who receives a heart transplant and a new lease on life. The power God entrusts to us through science and technology elicits worship whenever it works to restore human flourishing. But so many bioethical issues involve profound tragedies—an anencephalic newborn, conjoined twins, a child with a self-mutilating genetic condition, a teenager with untreatable and incurable bone cancer, a person who is HIV-positive, an accident victim left in a persistent vegetative state, a Haitian child dying from easily preventable cholera. These situations offer us opportunities to care and to convey the presence of Christ through shared suffering and sometimes the journey through the valley of the shadow of death. These tragedies inspire a somber worship that acknowledges the reality of evil, human frailty, the limits of science and technology, and the "not yet" character of Christ's victory over death. Such worship seeks God's comfort and grace and provides the setting to wistfully long for a new heaven and new earth, where death, sickness, and sorrow no longer occur.

I wish all Christians might be aware of bioethics as a fascinating, interdisciplinary field. It has the potential to enhance worship as well as preaching, counseling, and caring within the church. An interest in and fundamental knowledge of bioethics is most valuable in serving

parishioners facing difficult ethical dilemmas. As Christians, may God assist us in developing moral discernment consistent with his will and to his honor and glory.

Further Reading

Consult the web sites of major faith traditions and denominations. Many of them have developed thoughtful positions from their unique theological perspectives on various bioethical issues. These statements can be helpful in identifying one's own theological and moral values. The web has many sites addressing specific bioethical issues. You'll need discernment to judge the quality of these sites, and the possible theological and philosophical underpinnings of the authors. Recommended books include:

- Beauchamp, Tom L. and James F. Childress. *Principles of Biomedical Ethics*, 5th ed. Oxford: Oxford Press, 2008. Arguably the foremost scholarly work articulating theories and principles of biomedical ethics.
- Bouma III, Hessel, Douglas Diekema, Edward Langerak, Theodore Rottman, and Allen Verhey. *Christian Faith, Health & Medical Practice*. Grand Rapids, MI: Wm. B. Eerdmans Publishing, 1989. A Reformed Christian perspective on covenantal Christian bioethics and applications to healthcare, having children, abortion, end-of-life care, and caring for persons with HIV/AIDS.
- Cole-Turner, Ronald, and Brent Waters. *Pastoral Genetics: Theology and Care at the Beginning of Life*. Cleveland: Pilgrim Press, 1996. Two Protestant chaplains provide advice on pastoral care for persons experiencing genetic conditions and diseases.
- Groenhout, Ruth. *Bioethics: A Reformed Look at Life and Death Choices*, Grand Rapids, MI: Faith Alive Christian Resources, 2009. At just 136 pages, this is an accessible introduction to several bioethical issues, and includes questions for group discussion.
- Lammers, Stephen, and Allen Verhey, eds. *On Moral Medicine: Theological Perspectives in Medical Ethics*. Grand Rapids, MI: Wm. B. Eerdmans Publishing, 1987. An anthology of 105 articles featuring theological perspectives on major issues in bioethics

predominantly from Jewish, Catholic, and Protestant faith traditions.

- Lammers, Stephen E., and Allen Verhey, eds. *On Moral Medicine: Theological Perspectives in Medical Ethics*, 2nd ed. Grand Rapids, MI: Wm. B. Eerdmans Publishing, 1998. An updated anthology consisting of 128 articles featuring theological perspectives on major issues in bioethics predominantly from Jewish, Catholic, and Protestant faith traditions.