

Bioethics—Eleven Approaches

By Karen Lebacqz

Abstract: Using a case study, the author reviews 11 different approaches to bioethics, examining both their implications in clinical practice and their importance for clergy. In addition to the popular stress on patients' rights and principles in bioethics, the approaches include perspectives drawn from feminist ethics, phenomenology, ethnography, covenant views, virtue ethics, postmodernism, and casuistry. Lebacqz shows that each perspective may be important for stressing something different in the clinical setting, and suggests that clergy should be prepared to extend the range of views that may be operating in a given case.

Key Terms: beauty, bioethics, care, clergy, covenant, culture, power, rights, story

Maria sits quietly, waiting to learn whether she has BRCA1 or BRCA2—a gene for inherited breast cancer. Her eyes are fixed on the genetic counselor. Grimly, she covers her lips over her missing teeth. Her hands clutch the arms of her chair. Maria has recently lost one breast. She is here to learn whether she is at risk for losing the other breast. Several of her family members have had various forms of cancer. The geneticist talks about risk factors and diagnoses. Maria is silent. Finally, he tells her that her test has come back 'negative.' Maria looks appalled. The geneticist rushes to assure her that a 'negative' result is good. Finally, she understands. Then she asks him, "When do I get my prosthesis, so that I can be beautiful again?"¹

What ethical issues are hidden or obvious in this exchange? What insights does the field of bioethics offer for responding to them? What should a pastor know about bioethics in order to be helpful to Maria or her genetic counselor? Many pastors know of the four 'principles' enumerated by Tom Beauchamp and James Childress (and discussed below), but this approach no longer stands alone. Approaches to bioethics have multiplied. I believe that each of them may be important for highlighting certain aspects of Maria's encounter with the genetic counselor. In this essay I review briefly eleven different

approaches and their implications for Maria's situation and for clergy.

1. Patients' Rights

The Patients' Rights movement gained currency as a reaction to the perceived paternalism of medicine. Instead of "doctor knows best," advocates of patients' rights argued that competent adults should be able to make decisions about their health care. Understood as a claim that can be brought against others, a right can be either a 'negative' right to be left alone or a 'positive' right to be supported in seeking one's goals.

This approach would stress Maria's right to information. Maria has a right to know whether she is at risk from an inherited form of breast cancer. If she is at risk from BRCA1 or BRCA2, she has important decisions to make—whether to change her diet, whether to have her second breast removed in order to prevent the recurrence of cancer, and so on. The rights perspective will point to the fundamental importance of Maria's autonomous decision-making. It helps to illumine why information is so crucial for Maria, and why it is also crucial that the counselor be careful to ensure that Maria understands the information given.

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But does Maria have a right to the prosthesis that she so clearly desires? The answer to this question would depend on whether her ‘rights’ are rights to be left alone or rights to be supported in seeking her goals. In this culture, negative rights are more strongly stressed than positive rights.

2. Principles

Closely aligned with the patients’ rights movement is the current emphasis on principles. Popularized by Beauchamp and Childress’ massively successful *Principles for Biomedical Ethics*,² understanding health care decisions under the rubric of principles is probably the most common approach to bioethics today. Four principles have become standard fare. *Respect for autonomy*, from which we get the requirement that patients must give ‘informed consent’ to medical treatment, is the first principle and generally considered the most compelling. *Beneficence* reflects the traditional emphasis in medicine on doing good for the patient. *Non-maleficence*, or not-harming, reflects the Hippocratic maxim *primum non nocere*—first of all, do no harm. Finally, *justice* assures that any harms and benefits are distributed fairly.

Several of these principles apply clearly to Maria’s situation. Her autonomy should be respected. Beneficence and non-maleficence are also at issue: the genetic test will determine whether Maria is at risk and if so, the counselor will suggest ways to minimize risks and extend benefits. Justice issues become relevant in several ways. First, in some understandings of justice, Maria might be entitled to the prosthesis she desires in order to compensate for her life of hardship. Second, since Maria’s cancer may be inherited, other family members may be at risk. Justice might demand that they be informed even if Maria does not wish to do so.

Difficult dilemmas arise when principles push in different directions—for example, when respect for autonomy requires that Maria’s desires be honored but respect for justice requires that other factors be considered. The emphasis on principles in bioethics has therefore led some people to see ethics as largely

a matter of resolving ethical *conflicts*. This focus on dilemmas and conflicts has been much criticized in the last decade.

3. Covenant and Duty

Both rights and principles stress the autonomy of the patient. But some observers claim that any doctor-patient relationship is a covenant.³ As the great theologian Paul Ramsey once put it, “we are born within covenants of life with life.”⁴ Covenants are contrasted with contracts. A contract is limited, but a covenant is characterized by an ongoing commitment. Covenants are not rights-oriented, but duty-oriented: what do I owe the other person? In *Duty and Healing*, Benjamin Freedman notes that most care-givers use the language of duty.⁵ They treat patients not because they think patients have a ‘right’ to be treated, but because their role as care-giver brings with it certain duties or obligations. At the extreme end of such a view might be the ‘good samaritan’ laws that require physicians to stop and offer help at the scene of an accident. It is an obligation of some professionals to offer help even at risk to themselves. This is a covenant view.

If Maria does indeed have BRCA1 or BRCA2, a covenant view would dictate that the genetic counselor follow up and ensure that Maria gets appropriate treatment. It might also require outreach to her family. In one case, a genetic counseling team spent six months trying to contact a woman at risk who failed to follow up on her original visit. She kept breaking appointments and refusing to answer her telephone, but the team did not give up on her. They exhibited a covenant view in which they understood themselves to be bound to her in spite of her obvious resistance.

4. Casuistry

Not only do most practitioners think in the language of duty rather than rights, they also think in the language of cases. Is this case like the one that I

handled previously? How different is it? What does that difference tell me? In ethics, as in clinical practice, it is possible to start with *paradigm cases* and then seek to determine whether the current case is similar. If it is, the same solution might apply; if not, are the differences ‘morally relevant’? Such practical wisdom is casuistry, or case-based reasoning. What is usually in dispute, argue Jonsen and Toulmin in *The Abuse of Casuistry*,⁶ are not the principles themselves but the sense of how they relate to the specifics of the case. It is the specifics—and the skill to know which are relevant—that matter.

In Maria’s case, for example, the clinician looked at her history and her family history. That history suggested a strong likelihood of an inherited form of breast cancer. Thus, there are grounds for testing for BRCA1 and BRCA2. Negative test results mean that the clinician must now search for some other possible explanation for Maria’s cancer—an undiscovered additional gene that puts the family at risk, environmental factors, and so on. As he talks with Maria, he tries to decide what information to share and how to do it. Will she react the way his previous Hispanic patient did? How significant is the prosthesis to Maria, and why? Have his other patients done well with prostheses? Is there reason to think Maria will? As he struggles with these questions, the counselor is likely to be thinking about similar cases and how he handled them. Is Maria’s case sufficiently similar that it should be handled the same way?

5. Beneficence and Virtue

The casuistic approach requires considerable skill at discerning relevant similarities and dissimilarities in cases. Such discernment is also at the heart of the ‘virtue’ and ‘beneficence’ approach urged by Edmund Pellegrino and David Thomasma in *For the Patient’s Good*.⁷ The heart of medical practice, they claim, is the effort to do good for the patient. Beneficence is the core ethical demand. Hence, clinicians must be virtuous people, disposed to do the good. Only the *character* of the clinician guarantees good care. “The more we yearn for ethical sensitivity, the less we lean on rights, duties, rules, and

principles and the more on the character traits of the moral agent.”⁸ It is character that keeps the clinician in the hospital for long hours; it is character that sends the clinician home worried because this patient does not fit the typical profile and something else might be wrong. There is no substitute for the virtuous physician who wants to do the best thing for her or his patient.

In the beneficence and virtue view, Maria’s genetic counselor needs to be both virtuous and oriented toward Maria’s good. To be beneficent, he needs to see Maria in three dimensions: at the level of her physical health and risk of genetic disease, at the level of herself as a whole person who needs to have her beauty restored, and at the level of ultimate reality (or God). The physician who orients himself toward all three dimensions will honor Maria’s right to information and decision-making, but will also be oriented toward her ultimate good. He will take seriously her request for a prosthesis, as part of her whole good. But he will also be concerned about whether receiving a new breast will be adequate to ensure her self-respect and her sense of being loved. He will be patient with Maria, and exhibit other virtues as well, such as the classical cardinal virtues—fortitude, justice, temperance, and prudence.

6. Care

The emphasis on continued caring in the covenant view, on individual differences in the casuistic view, and on attention to the whole person in the beneficence view is akin to a view developed largely by feminists. Rather than grounding ethics in justice, rights, and principles, many feminists argue that ethics should be grounded in *care*.⁹ Distinctive to the care approach is the conviction that every person is different and therefore “one size does not fit all.” In this view, the emphasis is on the patient’s particularity. The care approach generally eschews principles and argues that good clinical care comes only out of *relationship*. Care as a foundation for ethics has been especially popular with nurses.

The genetic counselor exhibits care when he notes that Maria misunderstands a ‘negative’ result. He

does not leave her confused or frightened, but tries to reassure her that it is good news. Because he is a specialist and not her general practitioner, however, their relationship will be limited to a few encounters. The care model seems to fit best when we talk about the primary care givers rather than specialists who may enter our care-giving for only brief periods. Nonetheless, it is possible that even a brief encounter can exhibit care. In Maria's case, for example, a critical question will be how the genetic counselor responds to her demand for a prosthesis, so that she can be 'beautiful' again. Will he ignore the request? Will he find it amusing, in light of her missing teeth and aging face? Will he deal with it only in terms of its medical feasibility rather than in terms of its meaning to Maria? Or will he try to understand how this request reflects Maria's self-understanding? It requires relationship, time, and patience to offer care on this level.

7. Narrative and Story

An emphasis on Maria's self-understanding takes us to our next approach emphasizing narrative and story.¹⁰ The central claim here is that we *are* our stories. Each of us tries to live a coherent life in which illness, accident, and other events make sense in terms of our self-understanding and self-respect. Illness can be an assault on self-respect. Central to the narrative approach to bioethics, therefore, is (1) listening to the patient's story, (2) understanding what kind of a story it is, and (3) responding with a story that fits the patient's own story.

Arthur Frank proposes that patients tell three basic stories.¹¹ The first is the restitution story: illness or medical incident is an event to be overcome, so that the patient can go back to living his or her life as it once was. The second is the chaos story: illness or medical incident totally disrupts the patient's ongoing story and the patient flounders. The third is the quest story: illness or medical incident (especially chronic disability) becomes a challenge that both forces and enables the patient to find a new story to incorporate limitation or alteration of life plans.

It is clear that Maria wants restitution. She wants her breast restored so that she can be "beautiful" again. The genetic counselor is likely to think genetic information is central, but from a narrative perspective, Maria's story unfolds only when we learn that her breast is crucial to her self-understanding and self-respect. The narrative approach would locate the core demand of Maria's care-giving not in the genetic information but in her demand for a prosthesis. If a prosthesis is not medically recommended, the crucial question will be whether Maria can give up her desire for restitution and move to a quest story, so that she does not fall into chaos.

8. Phenomenology

While every patient brings a story, those stories are never merely idiosyncratic. Phenomenology is a method that focuses on the illness as experienced and seeks to give that experience a 'controlling presence' in the ethical analysis. However, it is not simply the *individual* patient's experience that is important. It is the *structures* of experienced meaning in everyday life that matter.¹² For example, almost all patients facing serious illness lose a sense of self. How does this affect the ethical demands of the clinical setting? Does it make sense to speak of autonomous decision-making when the patient has lost her sense of self? In our current medical care system, many of us receive care from relative strangers and this may make trust difficult if not impossible. Because diseases appear accidental to us, they raise fundamental questions of justice ("it's not fair") and of theodicy ("why did this happen to me?"). These are common structures that must be taken into account when deciding what is ethically required. The phenomenon of illness is not just personal but fundamentally communal and interpersonal. It points to the vulnerability of patients, the power of professionals, and the moral structure of care-giving.

A phenomenologist, for example, might point out how vulnerable Maria feels coming in to her counseling session with the geneticist. The medical language is strange to her—for example, she does not immediately know what the word 'diagnosis'

means, and she does not know that a 'negative' test result is good. Her silence might be taken as a sign of her estrangement and vulnerability. Maria is participating in an alien dialogue and must learn to use medical language (e.g. prosthesis) in order to communicate. The phenomenological view stresses the vulnerability of the patient and the importance of protecting her moral agency in this alien setting.

9. Ethnography

Like phenomenology, the ethnographic approach begins with the patient's suffering. But where phenomenology presumes commonality in patients' experiences of suffering, ethnography attempts to locate what is important in the 'local world' of the patient. Its emphasis is on cultural differences. Instead of seeing Maria as a 'case' of breast cancer, a personal 'story' of suffering, or even a communal experience of patient vulnerability, the ethnographic approach emphasizes how meaning and experience are affected by culture.¹³ Non-compliance by the patient may be not simply a form of alienation but a form of cultural resistance to dominant medical models and approaches.

Like the narrative approach, then, the ethnographic approach would stress Maria's experience of losing a breast as a key to her suffering. But where the narrative approach might simply try to 'hear' Maria's voice, the ethnographic approach would also stress Maria's social location. How does being Hispanic affect Maria's understanding of her breasts? Is her silence when the counselor is speaking a sign of vulnerability, as the phenomenologist might claim, or is it a sign of *resistance*? What does this encounter mean from Maria's distinctive cultural framework?

10. Feminist and Womanist Perspectives

But even attention to cultural differences is not sufficient. Feminist and Womanist commentators

insist that health care is at root a *political* enterprise, and that bioethics must attend to political dimensions.¹⁴ Power relations are central. Women have historically been and continue to be oppressed. Oppression is wrong. Oppressed people cannot easily exercise autonomy. Many feminists reject the language of 'care,' as it takes too benign a view of the medical encounter. How are relationships to be established or negotiated when power is unequal and when one party to the encounter is oppressed and the other is relatively privileged?

For example, Dorothy Roberts insists that general ethical mandates such as informed consent simply crumble when patients are women from marginalized groups, as is the case with Maria. Maria's silence might be taken as a sign of her oppression: the terms of the encounter are set by the medical professional, and it is a courageous effort toward liberation when she finally blurts out her desire for a new breast. Even language is deceptive, as Emilie Townes points out: in taking a genetic history, the counselor is likely to speak of Maria's 'extended family,' but this very term presumes that the nuclear family is the norm. Hence, feminist and womanist perspectives would begin by noting that Maria's situation as a woman of color makes almost inevitable that she enters the medical system from a position of oppression. Questions of justice and liberation therefore become central to an ethical analysis of the encounter. How can Maria be empowered in this situation? Does justice require that Maria be given the prosthesis that she desires?

11. Postmodernism

All of the above views share one thing in common: they do believe that it is possible to find a 'right' or 'wrong' action. Their modes of doing so may differ, but the fundamental conviction is that speaking of right and wrong make sense. Each urges a different comprehensive view, but all share the notion that comprehensive views are worthwhile.

By contrast, the very attempt to formulate a comprehensive theory would be anathema to postmodernists.¹⁵ Generally speaking, postmodernism

eschews ‘grand narratives’ and believes that meaning happens only in the microcosmos of small encounters. Thus, it is the “subtle nature of the interaction between doctor and patient” that matters most. Following Foucault, postmodernism also points to the dominance of the ‘clinical gaze’ and of clinical discourse. Indeed, some postmodernists would argue that medicine does not simply treat the body, as the body itself is *produced* through discourse. What the clinician sees is determined by training and by language patterns. Medical interventions ‘produce’ a certain kind of body—for example, a geneticized body, in which genes become most important.

This perspective helps to illumine some aspects of Maria’s encounter with the geneticist. He focuses on the body that he has learned to see through medical discourse—the geneticized body. She, on the other hand, focuses on a body that is also socially constructed—the whole body with two breasts that will make her ‘beautiful.’ Postmodern thinkers would no doubt point out that both sides of this encounter are limited in their discourse: each person ‘sees’ only some things. What is crucial is that the power of the professional makes his discourse and gaze dominant. Thus, Maria’s questions are in danger of being ignored altogether.

Implications for Clergy

This review is admittedly very brief, and not all perspectives or approaches are included. Those that are have been oversimplified. Even so, the array of approaches to bioethics can be bewildering. What are the implications for clergy? Those in specialized ministries such as hospital chaplaincy have an obligation to stay abreast of developments in bioethics that impact directly on their work. But these developments also have implications for local pastors. They may be called upon by health care providers or by patients. Minimally, this review suggests:

Clergy should attempt to recognize what framework is brought by the care provider or patient. Many will use the language of ‘rights’ or principles as a helpful way to sort out the clinical encounter. Knowing the strengths, but also the limits, of these

two dominant approaches may be important for breaking through seeming impasses.

Clergy can introduce additional frameworks. Care providers who take autonomy or patients’ rights as central can be helped to think about what they perceive as their duties and to ask what ‘care,’ ‘covenant,’ ‘beneficence,’ and ‘virtue’ might require of them. They can be asked whether they are seeing their patients simply as ‘cases’ and focusing on the medical dimensions that are primary in their training, or whether they are able to look at patients as whole persons and persons before God. Patients can be helped to ask what ‘story’ they bring, how that story is affected by their cultural background, and how it connects to the stories of other patients.

On occasion, clergy may have an obligation to challenge frameworks used by patients and care-providers. Clergy are probably most often called upon to answer the theodicy question—“why me?” Without neglecting this important question, attention to the many approaches to ethics in the clinical setting can suggest some other questions that are equally important. Is there oppression going on? Where does the patient feel alienated? What forms of resistance are available? How can the gap between clinical language and ordinary language be bridged? Introducing a political dimension may be the most difficult, but may also be crucial: getting all parties to think about power structures and how these affect encounters can move everyone to a new place of discernment. Perhaps the most crucial question is which perspective should be taken on an issue. To what extent does our very language tend to reflect dominant views and, hence, to contribute to cultural imperialism? How can we redress the oppression in our world and bring about more justice in the health care setting? Can compassion and justice work together?

Clergy can also ask what a specifically theological perspective might bring. Does theological language have something to contribute? What would happen if providers and patients were asked to consider their relationship as a covenant? Is restitution what we are promised by God, or are we promised something different—for instance, that we will never walk alone even when chaos seems to have taken over? Most important, in my view, is to ask what our human

destiny is, and how this destiny affects decisions about care-giving and care-receiving. Are the stories we create with our lives faithful stories? Are we serving the cause of justice? Are we becoming more loving?

Like Maria, all of us at root want to be 'beautiful.' This is where clergy have a particular role to play, in conveying God's love for every person no matter their disfigurement and disability. But this love cannot be conveyed simply in the moment of crisis. It is an ongoing task that must be incorporated into every aspect of worship and church life. Only then will Maria and the rest of us know that we are valuable, loved, and beautiful.

Endnotes

1. This case is adapted from Fernanda Carneiro and Roberto Dos Santos Bartholo Junior, "Maria's Desire: Considerations About a Moment of 'Genetic Counseling' for Breast Cancer," in Rosemarie Tong, ed., *Globalizing Feminist Bioethics: Crosscultural Perspectives* (Boulder, CO: Westview Press, 2000).

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4. Paul Ramsey, *The Patient as Person* (New Haven: Yale University Press, 1970), p. xii.

5. Benjamin Freedman, *Duty and Healing: Foundations of a Jewish Bioethic* (NY: Routledge, 1999).

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8. *Ibid.*, 122.

9. Susan S. Phillips and Patricia Benner, eds., *The Crisis of Care: Affirming and Restoring Caring Practices in the Helping Professions* (Washington, D.C.: Georgetown University Press, 1994).

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13. Arthur Kleinman, *Writing at the Margin: Discourse Between Anthropology and Medicine* (Berkeley: University of California Press, 1995); for a practical book on looking at cultural differences, see Geri-Ann Galanti, *Caring for Patients from Different Cultures: Case Studies from American Hospitals* (Philadelphia: University of Pennsylvania Press, 1991).

14. For feminist views, see Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992) and Rosemarie Tong, *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications* (Boulder, CO: Westview Press, 1997); for womanist views, see Emilie M. Townes, *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethic of Care* (NY: Continuum, 1998) and Dorothy E. Roberts, "Reconstructing the Patient: Starting with Women of Color," in Susan M. Wolf, ed., *Feminism and Bioethics: Beyond Reproduction* (NY: Oxford University Press, 1996).

15. Paul A. Komesaroff, ed., *Troubled Bodies: Critical Perspectives on Postmodernism, Medical Ethics, and the Body* (Durham, NC: Duke University Press, 1995).