



March 2001

Genetic Testing's "Soft Underbelly"

M. Therese Lysaught

Loyola University Chicago, mlysaught@luc.edu

Follow this and additional works at: https://ecommons.luc.edu/social_justice



Part of the [Bioethics and Medical Ethics Commons](#), [Christianity Commons](#), and the [Ethics in Religion Commons](#)

Recommended Citation

Lysaught, M. Therese, "Genetic Testing's "Soft Underbelly"" (2001). *Social Justice*. 25.
https://ecommons.luc.edu/social_justice/25

This Article is brought to you for free and open access by the Centers at Loyola eCommons. It has been accepted for inclusion in Social Justice by an authorized administrator of Loyola eCommons. For more information, please contact ecommons@luc.edu.



GENETIC TESTING'S "SOFT UNDERBELLY"

Genetic testing, one tool in the armamentarium of the new molecular medicine, promises real benefits in humanity's ongoing war against sickness and premature death. It seems likely that genetic technologies will, as is often claimed, "revolutionize" clinical medicine. Genetic testing alone has made it possible for physicians to:

- Alter prenatal management
- Provide more accurate diagnoses
- Predict conditions before symptoms appear (e.g., Huntington's disease)
- Identify predispositions to a variety of conditions (e.g., colon cancer, Alzheimer's)
- Tailor pharmaceuticals to individuals
- Treat patients *in utero*

These can be useful developments. Even so, the fact that the term "revolution" is used so frequently in conjunction with them should give us pause. Although it sometimes has more benign connotations, "revolution" is fundamentally a political word, one suggesting force, violence, and power. It traditionally refers to the overthrow of a regime, government, or social order.¹

The frequent conjunction of "genetics" and "revolution" is probably not accidental. One might argue that genetic testing also has a shadow side, a "soft underbelly" wherein it finds itself in alliance with broader social agents, a tool by which those who shape society wield power.



Dr. Lysaught is an assistant professor, Department of Religious Studies, University of Dayton, OH. Her article is adapted from a presentation at CHA's 14th Annual Invitational Theology and Ethics Colloquium, San Antonio, TX, in March 2000.

Christian Vision and Bio-Utopia

BY M. THERESE
LYSAUGHT, PhD

To distinguish genetic testing's positive aspects from its downsides, we who work in Catholic health care must begin examining these new technologies in the light of our faith tradition. In this article, as a first step in creating such a theological-moral critique, I identify:

- Four dimensions of genetic testing that belie its benevolent image
- Three central Christian beliefs that are useful in assessing or challenging various assumptions and practices associated with genetic testing

By bringing the latter to bear on the former, I hope to provide a model for how further theological-moral critique might proceed.

THE "SOFT UNDERBELLY"

To locate genetic testing under the rubric of "revolution," one would need to attend to the ways in which the practice functions as a means of power, how it contributes to the governance of individuals, and how it seeks to affect the social order.

These dynamics are abundantly clear in hindsight when one views the history of genetics, which is the history of eugenics. Contemporary practices of genetics cannot be understood without attention to the eugenic history that has shaped the discipline of molecular biology. Even the most cursory review of the history of eugenics reveals how it was used in the first half of the 20th century, serving as, in Joanne Finkelstein's words, "a mode of applied sociology": a tool for the maintenance of a specific social order.² Garland Allen and Kenneth and Bettylee Garver provide a good overview of the eugenics movement as it flourished in the United States during this period, identifying important socioeconomic and historical factors and some of the assumptions that guided the movement.³

Eugenics is not simply a thing of the past.



Certain of its guiding assumptions remain alive. It is difficult to see them, however, immersed as we are in genetic technologies. Finkelstein suggests, moreover, that contemporary biomedicine—including genetic testing—exercises its power in a far more subtle and invidious fashion than eugenics did.

How do the new genetic technologies give medicine—and society through medicine—power over our lives? I would argue that they do so in four ways.

Genetic Technologies Redefine Health and Disease With the molecular revolution, medical science ceased believing that disease is essentially caused by an external agent—a pathogen or carcinogen, for example—and began searching for an internal agent instead. Consequently, as Finkelstein notes, “genetic flaws are being redefined into sites of medical intervention.”²⁴

Medicine, whether it perceives disease to be the cause of a single-gene disorder (because they reduce immunity to certain pathogens) or as part of the oncological pathway, now looks to genes as the source of disease and disorder.

This relocating of the cause of disease changes the essential *meaning* of disease in at least three ways. First, one can now—in theory—have a disease but have no symptoms. Second, one can now be identified as having a disease before one is even born. Third, in an odd sort of way, one can “carry” a disease in one’s body, never suffering a symptom oneself but always serving as the disease’s potential transmitter. These are, of course, the presuppositions behind presymptomatic genetic testing, prenatal genetic testing, and carrier testing. Diseases are no longer episodic events that arise, are treated, and cured. They have become essential parts of who we *are*.

Not only can one have a disease with no symptoms, one can also be diagnosed as possessing an as yet symptomless disease for which no treatment exists. Indeed, for most of the conditions for which genetic testing can currently be done, no therapies are available. Not that this is in itself new; medicine has always lacked effective therapies for at least some illnesses. But it used to be that, even if treatment for it were absent, the diagnosis of a disease provided both the symptomatic patient and the physician with an answer

to a pressing problem—the presenting malady. Now, with genetic testing, the function of diagnosis and the labeling of disease states have become more ambiguous.

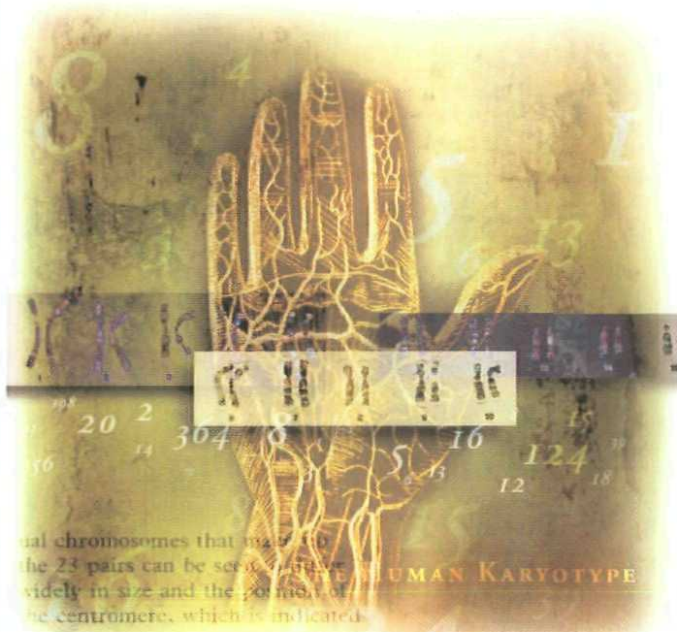
A genetic definition of disease also exponentially increases the range of possible diseases. Once the mapping work of the Human Genome Project is completed, the estimated 30,000 genes in the human complement will, in theory, become sites for disease identification.

Genetic Technologies Redefine Normality As more genes are identified and more locations for disease become available, more “ailments” may be “discovered.” Once one has a site upon which medical science can intervene, the temptation for medical science to do so increases. Traits that were previously considered “normal” tend to be reclassified as suitable for treatment. That

which can be treated becomes, almost by definition, “pathological.”

In this dynamic process, moreover, normality and abnormality are no longer defined by the community at large, measured by the impact of the trait on communal life. Instead, they become defined by the biotech industry as it decides which conditions and disabilities will be located and remedied and which will be, if not remedied, stigmatized. By the same token, the pressures of genetic reductionism suggest that remedies for “abnormalities” need no longer be messy, complicated, onerous social or behavioral practices. Now that such remedies are technological-genetic in nature, they would seem to be far more efficient, effective, and rational. Why should a problem drinker, for example, submit himself to Alcoholics Anonymous’s extended discipline if gene therapy will do the trick instead?

The standardization of genetic testing may subtly change the landscape of normality in another way. The search for innovative and efficient approaches to genetic testing has recently led to the development not merely of multiplex testing—testing for more than one genetic variant through a particular assay—but of the “gene chip.” A silicon analogue to the chips that power personal computers, the DNA chip gives biologists a way to assay potentially thousands of genes at one time. Now one’s physician might find





“abnormalities” no one would have suspected. And because it measures his or her variation against the norm at an unprecedented number of data points, the test will also reveal a huge number of *other* bits of information. Are these “abnormalities”? Are they medically significant? How is the poor patient to know?

Genetic Technologies Diminish Individual Autonomy Once the gene has been defined as the disease’s locus, and once a large number of disease sites have been identified, it will be only natural for the biotech industry to develop medications and treatments for them. The internal logic of genetic technology promises an increased “medicalization” of human life. This trend threatens to seriously diminish individual freedom and autonomy.

We know, of course, that misuse of genetic information in the realms of employment, education, or insurance is a danger. But Finkelstein suggests a more subtle and ironic threat to freedom: the way genetic testing can increase the dependence of individuals upon the medical profession.⁵ The mere *availability* of tests for hundreds of genes will encourage an increased medical surveillance of the individual body. As more tests become available and DNA chip technology is perfected, medical specialists will have access to an infinitely greater range of information. To test for one condition will be to test for them all. What would *informed* consent for such testing mean in this situation? As the human genome is mapped, more diseases are discovered, and more treatments for these diseases are developed, individual lives themselves become increasingly mapped by medicine. The logic that drives genetic technology seeks to bring more and more of human life—in all its aspects, nonmedical as well as medical—into medicine’s domain.

Will patients want such tests? Some clearly will. Some will desire information relevant to their immediate medical concerns. Others may be tempted with the promise of self-knowledge. But even if genetic tests are administered in response to patient desires, Finkelstein, for one, questions the nature of the apparent autonomy involved. For, she notes, in a technologically mediated society, interests, values, and desires are often cultivated by those who control the technology. More often than not, those who control the technology are motivated by a desire for profit.⁶

As we have seen repeatedly, especially over the past five years or so, biotechnological research is often initially justified by therapeutic rhetoric (children with diseases often figure prominently in such appeals). Cloning, it was argued, would provide a much-needed resource for the production of scarce genetically engineered proteins.

In a
technologically
mediated
society,
interests,
values, and
desires are
often cultivated
by those who
control the
technology—
more often
than not, those
individuals are
motivated by
desire for
profit.

Gene “therapy,” it was argued, would provide much-needed cures for tragic single-gene disorders that caused significant childhood suffering and early death. Sperm separation and selection technology was developed to prevent X-linked genetic diseases. Once researchers achieve the necessary technological breakthroughs, however, the focus of application tends to change. No longer are the technologies restricted to a therapeutic context; often, in fact, their therapeutic aspirations remain unrealized. Instead, the technologies are made available (at least in theory) for *any* application desired by the market. Thus researchers in New York announced last fall a possible gene “therapy” for baldness, and Microsort is made available to couples who simply wish to select the gender of their children.

Once technologies are available, applications must be found—and it is the job of the biotech company to cultivate in the general public a desire for whatever outcomes such technologies can achieve. Over time, as with ultrasound and amniocentesis, certain technological interventions become standard components in medical care—even if they provide no significant medical benefit.

In this way, individuals may find themselves coopted into submitting to technology that does not necessarily serve their interests. The practice of prenatal genetic testing is a case in point. As two students of the procedure have observed, “The majority of current genetic testing is geared to counseling for reproductive or prenatal decisions.”⁷ Note that prenatal diagnosis is *not* conducted to design therapies for the fetus, the child-to-be. As for prenatal counseling, couples who choose to be tested may in fact find themselves in a traumatic situation—as when, for example, they learn that the fetus has certain anomalies and they must decide what to do about it. Such “freedom” has large implications. The termination of one genetically defective fetus does not a eugenics movement make, but each act, when multiplied by thousands or millions, translates into a significant social impact. As for client autonomy, are not the decisions in such cases at least partly shaped by the practitioner who does the testing?

Genetic Technologies Promote a Vision of Utopia Behind genetic testing is a vision—a vision, as Finkelstein calls it, of “bio-utopia.”⁸ Each new development and discovery promises an end to disease as we know it (listen, for example, to the rhetoric surrounding gene therapy and human embryonic stem cells), as well as limitless human enhancement. Genetic testing is seen as a vital first step toward a kind of Holy Grail. Medicine, through genetic and allied technologies, promises the perfection of human life.



This is, of course, an eschatological vision, a vision of what the world will be like when the savior—medicine, in this case—comes into its own. Once one starts discussing eschatology, however, one leaves the realm of medicine and moves into the realm of theology.

THEOLOGICAL SOURCES OF RESISTANCE

If the genetic turn in medicine is indeed a revolution, if it entails a new exercise of power and is grounded in a particular eschatological vision, how should Catholic medical practitioners respond to it? Ought they simply profess loyalty to the new regime and accept practices that consolidate the new power? Or is the question more complex? Is resistance in order, at least to some degree? And, if it is in order, from whence might such resistance arise?

Catholics—and Christians generally—know themselves to be citizens of a different regime, namely, the church. Here, within the Christian theological tradition, practitioners and patients might find resources for a more nuanced and careful appropriation of the practice of genetic testing. Three convictions central to the Catholic tradition provide some critical purchase on these questions.

A Traditional Commitment to Healing Catholic thinking about any aspect of health care ought to begin with one of Jesus' primary activities: healing. The *Ethical and Religious Directives for Catholic Health Care Services* emphasizes the centrality of healing for a Catholic approach to health care; its very first sentences say, "The Church has always sought to embody our Savior's concern for the sick. The gospel accounts of Jesus' ministry draw special attention to his acts of healing. . . . In faithful imitation of Jesus Christ, the Church has served the sick, suffering, and dying in various ways throughout history."⁹

God (the tradition attests) affirms life, wellness, wholeness, and embodied flourishing. Medicine and its various technologies are rightly seen as elements of God's good creation, agents of God's healing. Those who practice the art of medicine should see themselves as ministers of God's grace and presence.

This commitment to healing provides us with substantive guidance for understanding the technology of genetic testing. In cases where genetic testing aids critical medical diagnosis and furthers therapeutic intervention, it is clearly a legitimate medical tool. Its use ought to be encouraged in the following sorts of situations:

- Diagnosing a presenting illness to determine the proper course of treatment for it
- Presymptomatic testing for illnesses (e.g.,

In the
Christian
tradition,
medicine is
not a consumer
commodity
supplied to
patients simply
because they
desire its
power.
Medicine is a
tool of healing,
a service to the
sick, suffering,
and dying.

colon cancer) in which early detection could be beneficial and effective treatment is available

- Carrier testing in counseling a couple at risk for transmitting a serious congenital illness (e.g., Tay-Sachs disease) accompanied by significant suffering and early mortality

Genetic testing in such situations furthers the end of healing. In others, however, its healing dimension is more dubious. One can clearly wonder whether the tools of medicine should be used for nonmedical purposes—employment testing, for example. What about tests designed to diagnose conditions for which no effective therapy exists? Of what medical use is it (aside from deciding whether to have children) to learn that one will someday be stricken with Huntington's or Alzheimer's? How could such knowledge be described as "healing"?

The Christian commitment to healing should also inspire questions concerning testing practices that simply increase the medicalization of human life. Such practices include:

- Testing for conditions for which patients are *not* at risk and for which no symptoms are presenting, especially multiplex testing
- Testing for a condition that does not significantly affect the patient's physical well-being but for which a putative treatment exists

Medicalization—which enlarges disease's role in the life of the person—is *antithetical* to a vision of healing. It is also antithetical to the Christian commitment to responsible stewardship of health care resources. In the Christian tradition, medicine is not a consumer commodity supplied to patients simply because they desire its power. Medicine is (or ought to be) a tool of healing, a service to the sick, suffering, and dying.

The Image of a Trinitarian God As Rev. Benedict Ashley, OP, and Rev. Kevin O'Rourke, OP, have said so well, "The basic principle of healthcare ethics is the dignity of the human person. . . . The goal of healthcare is to contribute to the full development of human persons. . . . Healthcare fails whenever it tends to depersonalize its clients by ignoring or restricting this freedom."¹⁰ Such a claim may seem on the surface rather formal, but Ashley and O'Rourke make it clear that the terms "dignity" and "full development," as they use them, are informed by a specific tradition rich with meaning.

A theological understanding of the dignity of the human person begins with a general recognition of the goodness of God's creation. We, along with all other living things, were called into being by God and are sustained by God's gracious goodness. As such, we are to be celebrated, nourished, and helped to flourish to the fullest extent



possible. What is more, the tradition affirms from the beginning that humans have the added grace of being created in the image and likeness of God.¹¹ This is a rich metaphor, thick with multiple meanings (creator, servant, sufferer, redeemer), pointing us toward that which we are called to be.

The fact that humans are created in the image of God points to the essence of God's nature, captured in the mystery of the Trinity. The Trinity is certainly a complex metaphor (not to mention a mystery), but also one that has been richly explored in the tradition. In the early church, Augustine's *De Trinitate* was the most influential explanation of the doctrine of the Trinity. Augustine, who interpreted the Trinity through the theological claim that God is love, described it as the dynamic interchange that exists between a lover, the beloved, and the love they share.

This image points to one fundamental significance of the doctrine of the Trinity, namely, the revelation that God's nature, the very essence of God is *relational*. God is not monolithic. God's essential reality is a community of persons, who, as love, live in perpetual self-giving and self-receiving.¹² A constitutive member of the Trinity is, moreover, the Son, the subject not only of the Incarnation and Resurrection but also of the Passion. The Son suffered. The experience of suffering is intrinsic to the very identity and being of the Trinity.

How might such a vision of the Trinity speak to genetic testing as a technology practiced upon persons created in a Trinitarian image and likeness? It would celebrate genetic testing insofar as it contributes to human flourishing, especially by preventing disease and promoting healing. In fact, the vision would remind practitioners that people flourish *most* fully when they are liberated from medical care—when they are well. By the same token, the vision would critique those genetic testing practices that decrease human freedom by increasing dependence on medicine. (When, for example, genetic testing confuses disease with identity, or multiplies interventions for trivial conditions, or increases medical surveillance of the body, it puts human beings into a kind of bondage to medicine.) And the vision of the Trinity would critique genetic testing that, on one hand, manipulates patients' desires in the interest of profit or social control, while, on the other hand, it promotes the myth that those patients are making autonomous choices.

But threats to freedom are not the only ways in which genetic testing may undercut human dignity and flourishing. Eugenic applications of prenatal genetic testing directly deny the goodness of God's creation and contribute in no way to the development of persons. Persons flourish most

fully, the trinitarian tradition affirms, as their connectedness in community and their network of relationships increases. That being the case, uses of genetic tests that handicap persons socially by stigmatizing them as intrinsically "abnormal" will obstruct their full development. Finally, the tradition affirms that suffering, though not to be sought out, is both a part of the human condition and theologically charged. As the *Ethical and Religious Directives* note:

For the Christian, our encounter with suffering and death can take on a positive and distinctive meaning through the redemptive power of Jesus' suffering and death. As St. Paul says, we are "always carrying about in the body the dying of Jesus, so that the life of Jesus may also be manifested in our body" (2 Cor 4:10). This truth does not lessen the pain and fear, but gives confidence and grace for bearing suffering rather than being overwhelmed by it. Catholic health care ministry bears witness to the truth that, for those who are in Christ, suffering and death are the pangs of a new creation. "God himself will always be with them . . ."¹³

An Alternative Eschatology This refusal to shy away from the reality of suffering and abandon those who suffer from genetic conditions brings us to our last point. Genetic technologies, as noted above, presume an eschatological vision. A different eschatological vision underpins the whole of the Christian tradition. The Catholic author Flannery O'Connor captures this vision in her characteristically startling fashion in her short story "Revelation," a story that, interestingly enough, begins in a physician's office. Near the end of the story, the major character, Mrs. Turpin, experiences a vision:

There was only a purple streak in the sky, cutting through a field of crimson and leading, like an extension of the highway, into the descending dusk. She raised her hands from the side of the [pig] pen in a gesture hieratic and profound. A visionary light settled in her eyes. She saw the streak as a vast swinging bridge extending upward from the earth through a field of living fire. Upon it a vast horde of souls were rumbling toward heaven. There were whole companies of white-trash, clean for the first time in their lives, and bands of black[s] in white robes . . . and battalions of freaks and lunatics. . . . And bringing up the end of

When genetic testing confuses disease with identity, or multiplies interventions for trivial conditions, or increases medical surveillance of the body, it puts human beings into a kind of bondage with medicine.



the procession was a tribe of people whom she recognized at once as those who, like herself and Claud, had always had a little of everything and the God-given wit to use it right. She leaned forward to observe them closer. They were marching behind the others with great dignity, accountable as they had always been for good order and common sense and respectable behavior. They alone were on key. Yet she could see by their shocked and altered faces that even their virtues were being burned away.¹⁴

O'Connor, herself a victim of the debilitating disease lupus, is here echoing the biblical vision of the Eucharistic and eschatological banquet found, among other places, in the Gospel of Luke.¹⁵ (This banquet is also invoked in the conclusion of the *Ethical and Religious Directives*.) Note the difference between Christian eschatology and secular eschatology. Unlike the secular vision, the Christian vision includes impaired people in its number: freaks, lunatics, the maimed, the blind, and the lame. In fact, as O'Connor shows, in the Christian vision these figures become *central*. In the Gospel, those who are healthy, prosperous, and socially successful—by all standards “perfect”—refuse to come to the banquet. They exclude themselves. O'Connor's vision adds an interesting twist: Here the healthy and socially secure are in the procession, but their perfections—“even their virtues,” as she puts it—are being “burned away.” O'Connor's immersion in the Catholic tradition informs her understanding that our pretensions to perfection, especially our “natural” virtues, are, in eschatological terms, vices.

A practice of genetic testing that promotes healing and the dignity of the human person should be celebrated as a ministry of discipleship and a creation of God's goodness. Insofar as such a practice sees itself as promoting a secular eschatology, however, it will find itself at odds with the meaning and purpose of Catholic health care. Practitioners and patients grounded in Christian eschatology will remember that the agent of human perfection is God, not genetics, and will recognize the genetically impaired as the privileged guests at the banquet. The Christian eschatological vision is a political vision—a vision of the Kingdom. We, confronted by the genetic revolution, must decide which of the two regimes will have dominion over our lives. □

I would like to thank Ron Hamel and the planning committee of CHA's 14th Annual Invitational Theology and Ethics Colloquium for providing me with the opportunity to prepare these remarks.

A practice of genetic testing that promotes healing and the dignity of the human person should be celebrated as a ministry of discipleship and a creation of God's goodness.

NOTES

1. See the *Oxford English Dictionary*, 2nd ed., which can be found online at <http://www.ohiolink.edu/db/oed.html>. Among the OED's definitions of revolution are “6b: An instance of great change or alteration in affairs or in some particular thing” and “7a: A complete overthrow of the established government in any country or state by those who were previously subject to it; a forcible substitution of a new ruler or form of government.”
2. Joanne L. Finkelstein, “Biomedicine and Technocratic Power,” *Hastings Center Report*, July-August 1990, p. 16.
3. Garland E. Allen, “Eugenics and American Social History, 1880-1950,” *Genome*, vol. 31, no. 2, 1989, pp. 885-889; and Kenneth L. Garver and Bettylee Garver, “The Human Genome Project and Eugenic Concerns,” *American Journal of Human Genetics*, vol. 54, 1994, pp. 148-158.
4. Finkelstein, p. 15.
5. Finkelstein, p. 13.
6. Finkelstein, p. 13.
7. Josef V. Kadlect and Richard A. McPherson, “Ethical Issues in Screening and Testing for Genetic Diseases,” *Clinics in Laboratory Medicine*, December 1995, p. 990.
8. Finkelstein, p. 13.
9. National Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, U.S. Catholic Conference, Washington, DC, 1995, p. 4.
10. Benedict Ashley and Kevin O'Rourke, *Healthcare Ethics: A Theological Analysis*, Catholic Health Association, St. Louis, 1989, pp. 2, 6.
11. *Ethical and Religious Directives*, p. 9.
12. See Margaret Mohrmann, *Medicine as Ministry*, Pilgrim Press, Cleveland, 1995, pp. 36-37.
13. *Ethical and Religious Directives*, p. 3.
14. Flannery O'Connor, “Revelation,” in *Everything That Rises Must Converge*, Noonday Press, 1970, pp. 217-218.
15. “When one of those who sat at table with him heard this, he said to him, ‘Blessed is he who shall eat bread in the Kingdom of God!’ But he said to him, ‘A man once gave a great banquet, and invited many; and at the time for the banquet he sent his servant to say to those who had been invited, ‘Come; for all is now ready.’ But they all alike began to make excuses. The first said to him, ‘I have bought a field, and I must go out and see it; I pray you, have me excused.’ And another said, ‘I have bought five yoke of oxen, and I go to examine them; I pray you, have me excused.’ And another said, ‘I have married a wife, and therefore I cannot come.’ So the servant came and reported this to his master. Then the householder in anger said to his servant, ‘Go out quickly to the streets and lanes of this city, and bring in the poor and maimed and blind and lame.’ And the servant said, ‘Sir, what you commanded has been done, and still there is room.’ And the master said to the servant, ‘Go out to the highways and hedges, and compel people to come in, that my house may be filled. For I tell you, none of those men who were invited shall taste my banquet’ (Lk 14:15-24).”