CONSCIENCE, COOPERATION, AND FULL DISCLOSURE

Can Catholic Health Care Providers Disclose “Prohibited Options” to Patients Following Genetic Testing?

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Modern research into genetics or, more precisely, “genomics”—which is the study not just of single genes but of the function and interaction of all the genes in the genome—reached its high point in April 2003 with the announcement that the entire human genome had been sequenced. Supporters of genomics research were quick to hail this achievement as a major scientific breakthrough that one day may revolutionize medicine in terms of how we prevent, diagnose, and treat human diseases that have a genetic basis.

If and when this revolution will occur is anybody’s guess. What we know right now is that the recent advances in our understanding of the human genome, coupled with innovative new technologies for analyzing genetic material, have had a transformative effect on the field of genetic testing. An umbrella term, “genetic testing” refers to procedures used to predict genetic risk factors, screen newborns for disorders, identify carriers of genetic mutations for particular diseases, establish prenatal or clinical diagnoses, and direct clinical care. At present, genetic testing is available or under development for approximately 1,100 genetic diseases in more than 550 laboratories in the United States.

Although genetic testing raises broad ethical issues related to, among other things, patient care, personal privacy, professional responsibility, and social justice—all of which deserve further research and study—this article focuses on an issue that, while admittedly more narrow, nonetheless raises important questions for Catholic health care providers.* Generally speaking, the issue has to do with the full disclosure of information to patients who have undergone genetic testing or will undergo it. In most cases, this is no issue at all because nothing restricts Catholic providers from sharing all factually relevant information with the patient. Some cases, however, present Catholic providers with a moral dilemma as to the content of the information they communicate to the patient.

These cases typically involve, on the one hand, patients who through carrier testing are found to be at risk of passing down an inheritable genetic condition to future offspring; and, on the other hand, patients who through prenatal testing are found to be carrying babies with severe congenital defects or chromosomal abnormalities. In such cases, full disclosure becomes a moral issue for Catholic providers because the provision of all factually relevant information would require such a provider to disclose options that are prohibited by church teaching.

In carrier testing cases, this would mean stating the options of contraception, sterilization, and in vitro fertilization with preimplantation genetic diagnosis, all of which are options available for patients who carry inheritable mutations and want to avoid pregnancy or avoid having a genetically affected child.* In prenatal diagnosis cases, this would mean stating the option of abortion or termination of pregnancy, an option that some

*Preimplantation genetic diagnosis is associated with in vitro fertilization and involves the creation of several embryos, testing the embryos for the creation of a particular genetic mutation, and implanting only embryos free of the genetic mutation.
women reluctantly choose to pursue after receiving the tragic news that the baby is stricken with a terrible anomaly. Though narrow, this issue has serious implications for Catholic providers that offer genetic testing to patients of reproductive age, and equally for patients who undergo such testing trusting that the Catholic provider will disclose all factually relevant information. It is an issue involving a theological "gray zone" because there is no specific church teaching regarding what information can be provided morally, and at this point it is unclear what the Catholic moral tradition allows.

This article is the authors' attempt to begin the conversation on this issue, which to this point has been largely unexplored, in the hope that greater moral clarity can be achieved. Since our focus is on the narrow moral issue facing Catholic providers, we do not consider the legal professional standards related to informed consent in the genetic context. It is sufficient to say that these are decidedly in favor of full disclosure of all factually relevant information. What is in doubt is whether it is morally permissible for Catholic providers to disclose information to patients about options prohibited by church teaching.

To set the stage for the moral analysis, we offer the following case.

**Nancy's Story**

You are a medical geneticist in a large Catholic acute care facility. Nancy has been referred to you by her obstetrician-gynecologist. Recently married, she and her husband wish to begin a family. However, one of Nancy's brothers has Duchenne muscular dystrophy, a genetic disorder found only in men and characterized by progressive muscle weakness that results in severe disability and death, typically by the early 20s. Nancy wonders whether she might be a carrier for the condition. She realizes that, if she is a carrier, there is a 50-50 chance that any male child she bears will inherit the genetic mutation and develop the disease.

You arrange for the testing with the hospital's genetics program. The results come back positive. Nancy and her husband now face an additional decision—whether to carry the unborn child to term or to terminate the pregnancy. Can you, as a medical geneticist who is employed by a Catholic provider and also personally opposed to abortion, licitly mention abortion as an available option?

One does not need to strain too hard to see the challenges that this type of case poses from a Catholic moral perspective. Unfortunately, there are no fast and easy answers as to what, if any, information about prohibited options can be disclosed by Catholic providers to patients like Nancy. The closest we get to one is in the *ERDs*, specifically Directive 54, which says: "Genetic
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Directive 54 is helpful to a point. However, it speaks more to the overall goal of genetic counseling and to the moral decisions prospective parents must make than it does to the content of the information that can be communicated morally by the Catholic provider. One could argue that the directive implicitly forbids the stating of prohibited options. However, this assumes that the overall goal of genetic counseling (i.e., to promote responsible parenthood and to prepare for the proper treatment and care of children) is better served by withholding factually relevant information from patients than it is by disclosing it within a broader moral discussion. This, we believe, would be reading into the directive what is not there and assuming too much.

Fortunately, there is an important source to which we can look for guidance on this issue—that is, the Catholic moral tradition, within which we find a theology of conscience. This theology, which can be supported by the principle of cooperation, suggests that full disclosure by Catholic providers—even the stating of prohibited options—is morally justified as long as the information is grounded in a Catholic moral vision.

Conscience

Though difficult to define, conscience is the moral core or deepest part of our moral selves. It is that sacred place within us where we dialogue with God and come to understand more fully who we are as persons made in God's image. As the Second Vatican Council so eloquently put it:

In the depths of his [or her] conscience, [the human person] detects a law which he [or she] does not impose on himself [or herself]. Always summoning him [or her] to love good and avoid evil, the voice of conscience can when necessary speak to his [or her] heart more specifically; do this, shun that. For [the human person] has in his [or her] heart a law written by God. To obey it is the very dignity of [the human person]; according to it he [or she] will be judged. Conscience is the most secret core and sanctuary of a [person]. There he [or she] is alone with God, whose voice echoes in his [or her] depths.

Authentic moral decisions are always made through a reflective process in which we discern what God is calling us to be and do in changing circumstances. Conscience gives us insight into this moral phenomenon and brings this knowledge to bear on concrete situations in which we have to make moral decisions that affect ourselves and others. Conscience is deeply personal but never individual, and it ultimately guides us to a judgment that we must follow lest we compromise our integrity and turn away from God.

While judgments of conscience are binding, they are not always free from error; and, because they are not error-free, we must proceed humbly, recognizing that the formation of conscience is a lifelong process and that we need always to do the work of informing our conscience in concrete matters.

An important aspect of informing our conscience involves consulting moral resources and the accumulated wisdom of others. Several religious and nonreligious resources are available to us when faced with an impending moral decision. These resources include, but are not limited to, Scripture, Jesus, the church, the community, role models, the authority of experts, and laws. The information supplied by these resources is essential in guiding us to the action that God is requiring and enabling us to do in the present moment.

Viewing the issue of full disclosure through the lens of a theology of conscience offers us moral insight into why Catholic providers can, within limits, state options that are prohibited by church teaching. As human persons called by God to develop and fulfill ourselves, we are obligated to make decisions that are true to our consciences, to what we, within the context of a community of believers, discern that God is calling us to be and do in the concrete. This is a difficult task that is made all the more difficult when we are not given complete information by those we trust to provide it. A basic moral responsibility of Catholic providers is to communicate factually relevant
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This directive is important for two reasons. First, it recognizes the primacy of conscience by stating that the patient should be given medical and moral information necessary to inform her or his conscience. In so doing, the directive suggests that Catholic providers cannot usurp the moral authority of a patient to direct her or his own life according to her or his conscience by failing to disclose factually relevant information. Second, the directive implicitly makes a crucial moral distinction between disclosing information and providing services that are not in keeping with conscience. It does this by indicating that Catholic providers need not honor all patient decisions, especially those that violate Catholic principles, but they must share factually relevant information with a patient so that she or he can inform her or his conscience. This moral distinction is indispensable if Catholic providers are going to fulfill their medical, moral, and legal responsibilities to patients while at the same time preserve their identity in a morally pluralistic society.

It is no mistake that Directive 28 comes under Part Three of the ERDs, which reflects on the nature of the patient-professional relationship. The individual directives within Part Three discuss critical features of this relationship and outline some of the basic rights and responsibilities of patients and professionals alike.

Yet it is in the introduction to the ERDs that we find another compelling reason, beyond that of informing conscience, why Catholic providers have a moral responsibility to disclose fully all factually relevant information to the patient. In a word, that reason is trust. One of the building blocks of the patient-professional relationship, trust is essential if the patient is going to feel free to share personal information necessary for effective care as well as heed the expert advice of the professional when it comes to following the care plan. If Catholic providers were to routinely and systematically refrain from disclosing factually relevant information, to what extent would that weaken the trust patients have in them and the health care professionals that practice in Catholic facilities? This is not a rhetorical question. It is one that must be taken seriously. The ability of Catholic providers to live out their healing mission in our broken world would be gravely undermined if the building block of trust were weakened or destroyed altogether.

Earlier, we qualified our argument for full disclosure by Catholic providers by indicating that such disclosure be done under certain conditions and within certain limits. Here we want to explain what we mean.

As we have shown, good moral reasons exist for providing patients with all factually relevant information, including that related to prohibited options. However, an important component of the disclosure process involves the way in which the information is imparted. Catholic providers cannot be flip when stating options prohibited by church teaching. Rather, they must ground this discussion in a Catholic moral vision that emphasizes the value of human life, the gift of human sexuality, and the proper transmission of human life. This is absolutely critical for the patient's own moral education and the formation of his or her conscience, as well as for the integrity of the Catholic provider. When it comes to actually stating the prohibited options, Catholic providers should do so in an objective fashion, pointing out that the services related to such options are not offered by the Catholic provider and explaining why this is the case. This is critical for full disclosure to be acceptable morally.

Here we would just like to add that, by stating options prohibited by church teaching, Catholic providers have an opportunity to offer much-needed moral guidance to patients in these difficult situations, something that would not occur if this were forbidden. It is not overestimating the significance of such a discussion to say that it could have a major impact on the future choices these patients make, not to mention the fact that it allows Catholic providers to continue to care for patients like Nancy during a very dark time in their lives. The alternative is that Catholic providers simply insulate themselves from the real-life decisions these patients are forced to make by severing care and transferring them to another provider, which would be required legally were Catholic providers not able to communicate all factually relevant information.

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leave patients like Nancy alone in their darkness, with nothing but alternative voices urging them to the very options that the church hopes they will reject. What is more, it could preclude Catholic providers from having genetic programs in the first place—which would mean that genetic testing services could not be provided within a Catholic moral framework.

**Determination of the Moral Object of an Action**

Determining the moral object of an action can be difficult. Leave patients like Nancy alone in their darkness, with nothing but alternative voices urging them to the very options that the church hopes they will reject. What is more, it could preclude Catholic providers from having genetic programs in the first place—which would mean that genetic testing services could not be provided within a Catholic moral framework.

**Cooperation**

Our argument in favor of full disclosure by Catholic providers, rooted as it is in a theology of conscience, can be supported by the traditional principle of cooperation when the prohibited options are stated to the patient with the right intention and through an appropriate process. The principle of cooperation has a long history in the Catholic moral tradition and has been very useful in helping to determine whether an individual's or institution's involvement in the illicit action of another is morally justified.

Putting it thus may seem abstract at first, but in reality the problem is one that Christians face daily as they try to live the Gospel values in a broken and imperfect world. The full disclosure issue may not fall within the realm of cooperation, because no one is as yet engaged in a morally illicit action. Nevertheless, we would like to illustrate how the stating of prohibited options by Catholic providers can be supported by the principle, since this is the primary concern among Catholic providers. Our purpose here is not to describe the principle of cooperation in detail, pointing out its many nuances and the differences in application among theologians. Rather, it is to consider the issue of full disclosure by Catholic providers in light of the six questions that must be answered in any case of cooperation.

1. **What Is the Object of the Cooperator's Activity?**

   This is the most basic question asked under the principle of cooperation. Traditionally speaking, the moral object is the action considered by itself, independently of its effects, and must be either morally good or indifferent. Determining just what the moral object of an action is can be difficult, but the key is to consider the action apart from the intention of the agent and the consequences that follow from the action.

   With this in mind, how would we characterize the object of the Catholic provider's activity if it were to state prohibited options to patients? It is quite straightforwardly described as communicating factual information to patients about their condition and the options available to them. Some might be inclined to argue that the moral object is promoting or condoning practices proscribed by the church. This, however, is a hard case to make, especially when the information is provided in an objective manner as part of the informed consent process and within the context of a Catholic moral vision.

2. **Is the Cooperation Formal or Merely Material?**

   This distinction is central to the principle of cooperation because formal cooperation is never morally permissible, whereas material cooperation can be permissible under certain conditions.

   On the one hand, the cooperator is engaged in formal cooperation when he or she intends or approves of the morally illicit action of the wrongdoer. Material cooperation, on the other hand, occurs when the cooperator helps the wrongdoer to accomplish a morally illicit action through her or his activity but does not intend or approve of the morally illicit action.

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3. **Is the Cooperation Immediate or Mediate?**

   Within the category of material cooperation, there is the distinction between immediate and mediate cooperation. The latter is what we would expect from health care professionals working in Catholic facilities. Hence, normally, full disclosure, even the stating of options prohibited by church teaching, would constitute material rather than formal cooperation.

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ate (which is generally always morally wrong) and mediate (which can be justified morally for a proportionate reason). Immediate material cooperation occurs when the cooperator, without intent or approval, actually performs the morally illicit action or provides essential support for it to unfold. Mediate material cooperation is significantly different in that the cooperator, also without intent or approval, simply helps the wrongdoer but only through an action that is secondary to the morally illicit action itself.

What would we say of the Catholic provider’s activity if the provider were to state the prohibited options to patients: Is doing so immediate or mediate material cooperation? Providing information about prohibited options clearly does not constitute immediate material cooperation. Neither the Catholic provider nor the patient would actually be engaged in a morally illicit action or “doing the deed” itself, so the first aspect of immediate is ruled out.

That leaves us with the question of essential support. Sharing information can, in some instances, provide essential support for a wrongdoer to perform a morally illicit action. Telling a bank robber precisely when the security guard leaves his post to go to the restroom could be essential support. However, full disclosure by Catholic providers, in the form of stating options about which the patient probably already knows and for which the information is obtainable elsewhere, does not rise to the level of essential support. The information is simply part of the factual picture and thus the disclosure of it could only be described as mediate material cooperation.

4. Is the Cooperation Proximate or Remote? Within the category of mediate material cooperation, there is another distinction—that between proximate and remote cooperation—that has to do with how close the cooperator’s secondary activity is to the morally illicit action itself. If it is very close, then the cooperator’s activity is considered proximate; if it is not close at all, then the activity is considered remote.

With this distinction in mind, how close would the Catholic provider’s secondary activity of stating prohibited options be to the actual performance of the morally illicit action of, for instance, abortion, contraception, or sterilization? It is not too difficult to discern that the stating of information about prohibited options is not closely tied to the morally illicit action. In fact, it is very far removed from the patient’s actually undergoing an abortion, taking contraceptive medications, or having a sterilization procedure, in that he or she would still have much work to do to get from the stating of the options to the actual performance of the morally illicit action.

Then, too, the patient might not even pursue a prohibited option after being told of them. So it is not as if the Catholic provider were disclosing the information in the knowledge that the patient will make use of it to commit a morally illicit action. For these reasons, the stating of prohibited options by Catholic providers would be remote mediate material cooperation, which can be morally justified for a proportionate reason.

5. Is a Proportionate Reason Present for Cooperating? This question asks whether there are sufficiently grave reasons for cooperating. It is an important question because, without a proportionate reason, cooperation in the morally illicit action of another, no matter how remote, would not be morally justified.

Do sufficiently grave reasons exist for Catholic providers to state the prohibited options available to patients? In the section on conscience, we articulated these reasons. We will not reiterate all that was said above but simply summarize the main reasons.

* First, there is the moral responsibility to inform the conscience of the patient, with all that this entails, including respecting the individual, fulfilling professional obligations, and meeting the legal requirements of informed consent.
* Second, there is the issue of maintaining patient trust, an essential aspect of the patient-professional relationship, which could be seriously undermined were Catholic providers to withhold information about the patient’s overall medical situation.
* Third, there is the need to provide moral guidance to the patient in a time of great need, which would not occur were Catholic providers banned from stating information about prohibited options.

6. Is the Cooperation Indispensable? This final question seeks to determine whether the cooperator’s activity is vital to the performance of the morally illicit action. Put another way, it is asking whether the wrongdoer could still perform the morally illicit action without the cooperator’s help.

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Two Analogous Positions

In answering these six questions, we have shown that full disclosure by Catholic providers can be supported by the principle of cooperation. When the prohibited options are stated to the patient with the right intention and through an appropriate moral process, full disclosure by Catholic providers can legitimately be considered remote cooperation justified for a proportionate reason. That this argument has some precedent within the more recent Catholic moral tradition and is not simply clever casuistry can be seen by comparing it to the morally analogous positions taken on other contentious issues.

The first issue involves providing information about prophylactics in HIV/AIDS educational programs, which was supported by the U.S. Catholic Conference Administrative Board in its 1987 document, *The Many Faces of AIDS: A Gospel Response.* This document articulates two positions regarding the church's pastoral response to the HIV/AIDS crisis. The first, which is most relevant for our purposes, is based on the assessment that in our morally pluralistic society not everyone will agree with the church's understanding of human sexuality and will not "act as they can and should" when it comes to preventing the spread of HIV/AIDS. The document states that in such situations "educational efforts, if grounded in the broader moral vision outlined [in this document], could include accurate information about prophylactic devices or other practices proposed by some medical experts as potential means of preventing AIDS." The document quickly points out that this is in no way "promoting the use of prophylactics, but merely providing information that is part of the factual picture."

Readers might contend that it is a mistake to refer to this document to support our argument because it was criticized strongly by some within the church. This might be true if the criticism centered on the issue of providing factually relevant information. However, the criticism was directed primarily at the second position taken in the document, namely, that a health care professional could presumably advise a person who was obviously going to put others at risk of contracting HIV/AIDS to use prophylactics. Our argument in favor of full disclosure is not susceptible to this criticism since it is insistent that Catholic providers not direct a patient to a particular option—especially one prohibited by the church—but merely outline all the options available to the patient in an objective manner and within the context of a Catholic moral vision.

The second issue involves informing female victims of sexual assault that emergency contraception is available to them elsewhere in the community, although the Catholic provider believes it would be morally illicit to administer or prescribe such medications to a woman, given where she is in her menstrual cycle and the remote possibility of an abortifacient effect. This position is supported by some Catholic providers that base their rape treatment policies on what has become known as the "ovulation approach." As we have seen in discussing Directive 36, this approach to treating female victims of sexual assault is predicated on the moral distinction, so vital for Catholic providers, between disclosing information and providing services that are not in keeping with church teaching.

By way of conclusion, we wish to emphasize that the approach we are recommending does not involve explicit or implicit approval of, or referral for, the prohibited options. Furthermore, the success of such an approach depends greatly on the adequate preparation of the health care professionals who will provide the information and counseling. As we noted previously, how this type of information is conveyed in a Catholic health care facility is critical, as are the beliefs, values, and attitudes communicated by the health care professional. We believe it is important for Catholic providers to be involved in genetic testing and counseling, but only if it is done professionally and in a manner that is grounded in and reflective of a Catholic moral vision.
NOTES

1. See GeneTests, a medical genetics information resource provided by the University of Washington, Seattle, and funded by the National Institutes of Health; available at www.genetests.org.

2. For an example of legal standards in favor of full disclosure, see Canterbury v. Spence, United States Court of Appeals for the District of Columbia Circuit, 464 F.2d 772 (D.C. 1972). Although this case focuses primarily on the duty of physicians to disclose information about risks of proposed treatments, it goes into great detail about the overall duties of physicians to obtain true informed consent, which requires, in part, disclosure of all reasonable options available to patients so that they can direct their care accordingly. As the court states, "True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeable the options available and the risks attendant upon each" (emphasis added). Moreover, the court states that "it is evident that it is normally impossible to obtain a consent worthy of the name unless the physician first elucidates the options and the perils for the patient's edification." For an example of professional standards in favor of full disclosure, see American Medical Association, Council on Ethical and Judicial Affairs, Code of Medical Ethics, 2004-2005 ed., AMA Press, Chicago, 2004, Section 2.12 ("Genetic Counseling"), pp. 40-42.


12. It should be noted that church teaching does not require Catholic providers to refrain from providing emergency contraception to female victims of sexual assault on the basis of their ovulatory status. We point this out only to highlight the fact that the provision of the medications, even when the woman is at or around the time of ovulation, does not violate church teaching as it currently stands. For a further discussion of this issue, see Ronald P. Hamel and Michael R. Panicola, "Emergency Contraception and Sexual Assault," Health Progress, September-October 2002, pp. 12-19, 51.