Professing the Gift of Life: Responding to Requests for Genetic Testing in Early Pregnancy

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ABSTRACT: Healthcare providers have two reasons to be cautious about offering early prenatal genetic testing, for it is now the "standard of care" and something desired by many parents. (1) Doing so can easily constitute proximate material cooperation with the great evil of abortion. (2) More deeply, and even when parents are not abortion-minded, it can be at odds with the great good of human life, understood as a pure gift from God the Creator. Providers should therefore make such testing available only when it is specifically needed to offer better care if a baby is found to have a genetic anomaly. They should adhere to this limit even if it might involve conscientious objection to the policies of "professional" bodies or of the state, and they should be prepared to offer parents some psychological and spiritual assistance in coping with their uncertainties and fears.

WITH THE DEVELOPMENT and routinization of methods of testing for chromosomal and genetic anomalies (especially, but not only, Down syndrome) in unborn babies, including mid-trimester amniocentesis

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several decades ago (promoted by the March of Dimes),[1] and more recently techniques for first-trimester screening, offering these methods is now widely regarded as the standard of care[2] and many parents avail themselves of this opportunity for testing. With the frequent abortion of babies who are found by these methods to have such anomalies, conscientious providers of health-care services to pregnant women might naturally wonder about the ethics of offering genetic testing.

The most obvious ethical problem concerns cooperation with the evil of abortion. What sort of cooperation is entailed when offering genetic testing to parents who might abort a child found to have a genetic anomaly? Is there any way to minimize this cooperation? I will address these questions first. I also want to propose, however, that, even apart from the connection between genetic testing and abortion, there are still deeper moral, and even spiritual, matters at stake. These matters concern our relationship with God and his creation. They call first- and mid-trimester genetic testing into question.

I argue here that physicians and other health-care professionals ought, as much as possible, to refuse to offer this sort of genetic testing, unless it is clear that it will make it possible to offer better care to a baby found to have a genetic anomaly. The reasons for refusing genetic testing unless necessary for the eventual good of the baby add to the list of reasons that have to do with the small but real risk posed to the baby from invasive testing methods themselves (like amniocentesis). That is, I am offering reasons that apply even if testing can now or could in the future be accomplished solely by entirely risk-free methods.

Genetic Testing and Cooperation in the Evil of Abortion.

Our understanding of cooperation with evil owes especially to the thought of eighteenth-century moral theologian Alphonsus Ligouri in his *Theologia*

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[1] See, e.g., Eileen Ogintz, "Prebirth Defects," *Chicago Tribune* (3 July 1988): www.chicagotribune.com/news/ct-xpm-1988-07-03-8801120627-story.html (accessed 16 September 2019).

[2] See, e.g., Mark W. Leach, "ACOG Issues New Prenatal Testing Guidelines" (2016): prenatalinformation.org/2016/04/29/acog-issues-new-prenatal-testing-guidelines/(accessed 16 September 2019).

Moralis.[3] The following is my own summary of the types of cooperation and the principles that govern whether cooperation would be morally good or evil.

If one in some way facilitates an evil action, one is cooperating with that evil action. If one does so *in order to* help bring about that evil action – if one intends the facilitating – then one is *formally* cooperating. Just as to intend to perform an evil action is by definition evil, so to intend to facilitate the performing of an evil action is evil. Thus formal cooperation with an evil action is evil – never morally licit.

If one does not intend the facilitating, but rather only foresees it,[4] then one is *materially* cooperating. If one materially cooperates *by directly taking part in the evil action,* this is *immediate* material cooperation. If – and this is doubtful – there is a meaningful distinction between formal and immediate material cooperation, the latter is nevertheless also (and for the same reason) evil – that is, never morally licit.

If one materially cooperates *in some other way* (that is, *not directly taking part in the evil action*), then this is *mediate* material cooperation. This must in turn be divided into two types, the line between which is sometimes less clear than the lines between formal and material cooperation and between immediate and mediate material cooperation.

If one mediately materially cooperates by performing an action that *"closely" facilitates* the evil action, this is *proximate* material cooperation; if one does so by performing an action that *"distantly" facilitates* the evil action, this is *remote* material cooperation. *Closely* and *distantly* are probably best thought of here in terms of how many other free choices (made by others) are required in order for one's own action actually to have the effect of making possible the eventual evil action.

Obviously these are relative concepts and terms, so that the line between proximate and remote cooperation is not always entirely clear. There are, however, some case – probably even many cases – in which it is fairly obvious which category better applies.

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[3] For a more contemporary treatment (with references to key passages from Ligouri), see Germain Grisez, *Difficult Moral Questions,* vol. 3 of *The Way of the Lord Jesus* (Quincy IL: Franciscan Press, 1997), pp. 871–97.

[4] On the "intention/foresight distinction," see Christopher Kaczor, *Proportionalism and the Natural Law Tradition* (Washington DC: The Catholic Univ. of America Press, 2002), pp. 64–79.

In the case of mediate material cooperation, whether proximate or remote, one is not intending, in any sense, the facilitating of another's evil action. That facilitating is within neither the immediate intention (understanding *intention* as what defines the moral object)[5] nor the remote intention (understanding *intention* in the usual sense) of one's action. Rather, such facilitating is considered *praeter intentionem* – outside one's intention.

Using the doctrine of double effect, moralists have regularly argued that an action that will cause an evil effect that is *praeter intentionem* rather than intentional could cause something evil to come about and yet could be morally acceptable if there is also a proportionate reason for choosing the action (that is, some proportionate good to be accomplished). The first of these two criteria distinguishes the doctrine I am describing from proportionalism (the ethics that holds that an action's moral evaluation derives only from a consideration of its likely consequences).

How good must a good be in order to be a proportionate one? This depends on three things. One of these is, of course, the magnitude of the evil that action will, *praeter intentionem*, cause. A greater evil (like the killing of an innocent human being) would require a greater good.

The second is the likelihood that the evil will in fact come about. That is, in cases of mediate material cooperation with evil, it depends on the likelihood that other people will make the choices that they need to make in order for the evil act actually to be performed. A greater likelihood will require a greater good to satisfy the criterion of proportionality.

The third consideration is how proximate or remote one's cooperation in that eventual evil act will be. One must ask how many other people's free choices will be necessary in order for one's own action actually to make possible the eventual evil one. This is a kind of measure of the degree of responsibility one will have for that eventual evil action. A greater proximity to that evil action (that is, a greater degree of responsibility for it) will require a greater good to in order be proportionate to the eventual evil. Only by taking into account all three of these considerations together – the magnitude of possible evil in which one is cooperating, the likelihood that the evil will

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[5] On the meaning of "object," see Kevin E. Miller, "How to Talk about the Use and Abuse of Natural Family Planning: The Importance of Accuracy in Translation and in Description," *Linacre Quarterly* 79 (2012): 400–02.

actually come about, and the proximity or remoteness of the cooperation – can one assess how good the intended result of the action must be in order for the criterion of proportionality to be satisfied, that is, in order for the cooperation in evil to be justified.

It seems that when a pro-life health-care professional offers – either by making a suggestion or by complying with a patient's request – early-pregnancy genetic testing, this constitutes proximate material cooperation in a likely and very great evil. Again, it seems that today patients who avail themselves of such testing often do so with the strong intention of aborting the baby – thereby killing an innocent (and most vulnerable)[6] human being – if the baby tests positive for an anomaly. And not many chosen actions need to intervene between the referral for genetic testing and the decision to abort in order for the former actually to facilitate the latter.

Can the cooperation be mitigated, for instance, by requiring patients to attest that should an anomaly be found, they will not abort their babies? I confess that I am not persuaded that this would typically mitigate the cooperation very much. In order for it to do so, at least one of the following would have to be true: either the attestation would be legally binding (something that would be at best extremely dubious, under current constitutional law), or the provider would be (somehow) morally certain that the patient's attestation is fully sincere and that the patient will not change her mind. I say "her" because – again, under current constitutional law – the decision whether or not to abort is entirely the mother's.[7]

Absent mitigation, I think that securing the attestation would still be fully necessarily in order for the cooperation entailed in offering genetic testing to be morally justified, since without it the provider has *no* reason to think that he or she is *not* – proximately – cooperating in the grave and likely evil of abortion. I also think that an additional condition – besides securing the attestation – would then be necessary to justify offering testing: namely, that better care for the baby (if found to have a genetic anomaly) would be made

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[6] This aspect of the evil of abortion ought not be forgotten. See John Paul II, *Evangelium vitae* (1995) §58. This and other Catholic Church documents referenced herein can be found at the Holy See's website, www.vatican.va.

[7] Even spousal *awareness* laws, let alone spousal consent ones, are unconstitutional according to current precedent: *Planned Parenthood v. Casey*, 505 U.S. 833 (1992).

possible by the early testing. What I do not know is whether – and, if so, how often – this is likely to be the case. It is clear that having a care plan and resources in place at birth can at least sometimes be helpful for babies with a genetic (or other) anomaly. (This includes, for babies with very severe conditions, perinatal hospice, a recent and most welcome development.)[8] The question is whether making the best care available at birth requires knowing in the first or second trimester that there will be need for it. Absent this requirement, it is unclear at best what proportionate good there could be.

In fact, even if the provider is otherwise convinced of the patient's sincerity in attesting that she will not have an abortion, it seems to me that the requirement still applies that early testing would be necessary in order really to make the best care (at birth) possible. In situations of great pressure, one's sincere commitments sometimes give way. Surely, for at least some genuinely sincere people, the knowledge that one's baby will be seriously disabled will give rise to considerable psychological pressure from within. If one "needs" testing because one cannot handle *not* knowing *whether* the baby has, say, Down syndrome, then how realistic is it to think that one will be able to handle knowing *that* the baby *does*? The testing will also create real vulnerability to considerable social pressure from without in our "culture of death," with its failure to see that freedom is oriented toward truth.[9] This pressure could even come from the baby's father. I think that only if a patient is committed *to not having* an abortion *and to providing* some concrete sort of care that the testing would make possible (and that would not otherwise be possible) can the provider be sufficiently assured that he or she is not actually proximately facilitating the great evil of abortion. Obviously, if no such care exists, then no such commitment can exist.

Deeper Moral and Spiritual Matters

What ways of approaching the bearing of a baby (carrying a new human life and giving birth) are consistent with a proper recognition of one's

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[8] On this, see, e.g., Tad Pacholczyk, "The Welcome Outreach of Perinatal Hospice," *Making Sense of Bioethics* (January 2019) www.ncbcenter.org (accessed 16 September 2019).

[9] John Paul II, *Evangelium vitae* §§18–19; cf. John Paul II, *Veritatis splendor* (1993) §4 and passim.

relationship with God as the *infinitely* transcendent Creator and of creation as God's *pure* gift? And what does this have to do with the practice of medicine in particular?

We value medicine as a profession. What is a profession? What makes a profession as such noble, such that calling medicine a profession should matter to us? I am drawing here from the thought of Leon Kass. The original professions were theology, medicine, and law. Most obviously in the case of theology (*faith* seeking understanding) but also in the case of the others, a profession involves a kind of commitment (even touching much or all of one's life), as in a "profession of faith." This is most basically what makes a profession a profession. That a profession involves a certain kind of education ("the learned professions") and/or that it can involve the possibility or even the requirement of state licensure are secondary considerations.

What does medicine profess? The good of human health. Obviously the definition of "health" is controversial. Kass suggests something like the well-functioning of the (human) organism as a whole.[10] Even though it is not the goal of medicine to prolong life at all costs, nevertheless human health presupposes human life. If health is a good worth professing, this is because life is too. Aquinas, if indirectly, teaches this: the good of bodily integrity (closely related to health) is an aspect of the good of bodily life itself, such that loss of the former is analogous to loss of the latter.[11]

Human life is, furthermore, a gift from God our Creator. What I want to emphasize is that human bodily life, as the *very existence* of the embodied human person, is a gift. Of course, *human* life is especially a gift, since the human soul is an intellectual soul, and therefore spiritual. It is created directly by God.[12] Furthermore, the human being is created in the image of God, with a capacity and even desire to receive the supernatural gift of a share in God's own life, culminating in the Beatific Vision.[13] Additionally, because the human

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[10] Leon R. Kass, *Toward a More Natural Science* (New York NY: The Free Press, 1985), chs. 6, 8.

[11] Aquinas, *Summa theologiae* I-II.65.1: "Et ideo *sicut* per publicam potestatem aliquis licite privatur totaliter vita propter aliquas maiores culpas, *ita* etiam privatur membro propter aliquas culpas minores."

[12] Aquinas, *Summa theologiae*, I.90.3; *Catechism of the Catholic Church* §366.

[13] Henri de Lubac, *Catholicism* (San Francisco CA: Ignatius, 1988), esp. ch. 1; *The Mystery of the Supernatural* (New York NY: Crossroad, 1998), passim. As is well

being is an embodied spirit, he or she (alone among creatures) exists for his or her own sake, as Aquinas suggested,[14] and Vatican II's *Gaudium et spes*[15] and John Paul II[16] taught us. Thus the human being is, as it were, a gift to him or herself before being a gift to others. This is not unimportant or irrelevant for the topic of respect for human life!

But what I most want to emphasize here is that the *life* of the human being *is* a gift from God, our infinitely transcendent Creator. God had no need of *any* sort to create anything, and yet did so. This point is in principle something discoverable by human reason, a philosophical insight. There is evidence of this in Aquinas's "third way"[17] and his *De Ente et Essentia*. That God is the Creator and that creation (and so human life in particular) is the gift of God can be the object of a profession, just as the recognition that the good of human community needs to be ordered by justice can be the object of the legal profession.

Furthermore, these realities (God as infinitely transcendent Creator and creation as gift) are made known first by revelation (especially by Genesis 1:1 as interpreted by 2 Maccabees 7:28), and then appropriated by philosophical reason. Jewish and especially Christian thought exceeds Platonic and Aristotelian thought in recognizing these realities, as Robert Sokolowski has pointed out.[18] Especially for this reason, we can in fact say that a profession of God as Creator and of creation as gift is part of our profession of faith.

Medicine's profession that health is a great good is not unrelated to the Christian profession of creation (including human life) as gift. When medicine takes this reality into account, it is not being influenced by (let alone allowing to be imposed upon itself) something that is simply extrinsic to it. Rather it is

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known, this is a major theme of de Lubac's life work. The discussion and controversy that it continues to generate is beyond my scope. But as just three examples of its appropriation by the contemporary Magisterium, see, e.g., Vatican II, *Gaudium et spes* §22; John Paul II, *Redemptor hominis* (1978) §10; and most especially, Benedict XVI, *General Audience,* 16 January 2013.

[14] Aquinas, *Summa theologiae* I-II.64.1.

[15] Vatican II, *Gaudium et spes* (1965) §24.

[16] As just one of many possible examples, John Paul II, *Veritatis splendor* §13.

[17] Aquinas, *Summa theologiae* I.2.3.

[18] Robert Sokolowski, *The God of Faith and Reason* (Washington DC: The Catholic Univ. of America Press, 1995), esp. ch. 2.

being formed by something to which it is intrinsically related and open. If medicine professes the good of human health, and if this good presupposes the good of human life, and if human life is a gift from the infinitely transcendent Creator, then medicine is intrinsically open to the profession of human life as a gift from the infinitely transcendent Creator.

What does this have to do with genetic testing, especially when such testing is not clearly needed to provide better care for a baby with a genetic anomaly? I want to suggest that the technological paradigm[19] that brings about the desire for knowledge of whether one's baby will have such an anomaly is in the end not compatible with profession of God as our Creator and of creation as God's gift. In the end, this paradigm sees the world as matter in motion,*and as an object of control.* Seeing the world in this way is, I contend, fundamentally incompatible with seeing the world as constituted by a *given* form and purpose and, still more fundamentally, as *gift*. This is why this paradigm is not only morally but also spiritually faulty and requires a spiritual response – a "pedagogy of desire," in Benedict's words.[20] The connection between this paradigm and genetic testing is obvious when genetic testing is pursued with the intention that if an anomaly is found, the parents will abort the child. And here especially we also see the moral problem with the technological paradigm.

But, I contend, this connection exists even when there is no intention to abort, unless the testing is done as part of the pursuit of some real good for the child, some way of caring for the child's health at birth that cannot otherwise be obtained. The psychological urge to use some technological means to find out what *kind* of life a baby is going to have is, I think, itself a kind of desire for control. It must be rather sharply distinguished from a disposition of receptivity to human existence, and therefore to human life, as gift.

Were someone to object that this also constitutes an objection to the (very routine) use of ultrasound to find out whether a baby is a girl or a boy, I would quickly respond, yes, very probably so, to say the least. I think that this is also a reason for adults generally not to pursue genetic testing to see if they

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[19] See Leon R. Kass, *Life, Liberty and the Defense of Dignity* (San Francisco CA: Encounter, 2002), pp. 29-49; Benedict XVI, *Caritas in veritate* (2009) §§70-77; Francis, *Laudato si'* (2015) §§101-23.

[20] Benedict XVI, *General Audience,* 7 November 2012.

themselves will or are likely to develop various serious but unpreventable conditions that might run in their families.

A way of seeing the connection between the desire inherent in the pursuit of genetic testing (when not needed as part of the pursuit of health care) and the attitude of seeing creation as an object of control rather than a gift (with God as Creator) is as follows. It would seem that this desire must reflect some sense of a psychological need on the part of a parent to know how his or her child's life (after birth) will affect that parent.

But *why would there be such a "need"*? I suspect that it would – at least most likely – be grounded in a desire to "control" the situation of that child's life by "preparing" oneself, if only psychologically (though at the same time together with one's spouse and perhaps others) for the reality of the birth of a child with a genetic anomaly. *This kind* of psychological "preparing"[21] is *itself* a kind of seizing (or attempting to seize) control. At minimum, it reduces the emotional part of *oneself* to an object of technological control. If one thinks that one's emotions are "controlled" *by* the situation of not knowing the condition *of one's baby* and that one therefore needs to seize control back *by finding out what that condition is,* then one is likewise reducing the baby to an object of control rather than welcoming him or her as a gift from the Creator.

It might be objected that the desire for "preparation" for the birth of a disabled child can be a healthy and good thing – for example, if the preparation were to take the form of prayer, or planning. But some people seem to think that prayer for God's help in being good parents – *whatever* the child's needs – is not enough. This perception typically – unless there is *specific* reason to think otherwise in a particular case – reflects a spiritual problem: an inappropriate desire for control, that is, a lack of appropriate sense of creation as God's gift, and therefore of God as Creator.

My claim about the spiritual problem inherent in this desire is related to what Aquinas says in making the distinction between the virtue of studiousness (a part of temperance, which moderates our desires) and the vice of curiosity. One way, Aquinas says, in which the desire for knowledge can be wrong and vicious is when there is a desire for knowledge of creatures that is not referred

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[21] Not, please note, the only possible kind; more concerning which in this essay's conclusion.

to its due end, the knowledge of God.[22] But a desire for knowledge of creatures that stems from a desire for control is *ipso facto* not referred to knowledge of God as his really is, namely, as Creator. Therefore it is a kind of curiosity in the sense that Aquinas calls a vice.

All of this constitutes a deeper reason for the physician conscientiously to refuse to provide genetic testing in early pregnancy when this is not necessary to enable better care for the baby when born.

Conclusion

Leon Kass suggests that the physician should profess the good of health not as the patient's master – as in the largely discarded "paternalistic" model of medicine – nor as servant – as in the model of medicine that sees the physician as distributor of whichever of those tools that he is licensed to provide that a patient may happen to desire – but rather as *teacher.* Health, Kass suggests, comes more from within than from without, and it is the physician's role to teach the patient how to maintain and, when necessary and possible, to recover health, including but by no means only by accepting the physician's prescriptions of medications, referrals for surgery, and the like.[23]

Precisely as teacher, the physician ought to refuse to provide those things that would not serve anyone's health and *especially* those things that are *at odds with* a proper understanding of human health, *and therefore* human life, *as a gift from the Creator himself,* who *precisely as* infinitely transcendent Creator is nearer to us than we are to ourselves. John Paul II speaks of the importance of conscientious objection[24] on the part of health-care professionals to those actions that constitute attacks on human life. In light of his analysis of the foundations of the culture of death in which those attacks are widespread and broadly accepted, including the loss of sense of God as Creator and of the creature,[25] I suggest that there ought also to be refusal to cooperate in those actions *that contribute to this loss of the sense of creation as the Creator's gift*. For these deeper moral and spiritual reasons, as well as for those having to do with cooperation with evil, physicians ought to refrain from offering genetic

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[22] Aquinas, *Summa theologiae* I-II.167.1.
[23] Kass, *Toward a More Natural Science,* p. 200.
[24] John Paul II, *Evangelium vitae* §§73-74, 89.
[25] John Paul II, *Evangelium vitae* §22.

testing in early pregnancy, except in those cases in which it is necessary to provide the best care for the baby's health.

What can the physician or other professional offer to parents who are deeply worried about whether their baby will have a genetic anomaly resulting in disability? As a very brief concluding suggestion, I think that something like a combination of the sort of discernment of spirits explained in Ignatius of Loyola's *Spiritual Exercises* and contemporary cognitive therapy might be of help. The latter can enable people to *allow* understandable but unhelpful worries, fears, and other emotions to exist without being *controlled by* them. The former can help enable people to see whether the spiritual movement underlying a desire is or is not in keeping with God's loving plan for their lives.

Will a typical conscientious physician always, or even usually, be able to convince a given mother and/or father to put aside the desire for genetic testing as rooted in the movement of a bad spirit? Probably not. Probably more than a few parents will simply take their request elsewhere. But a physician can at least decline to give in to parents' requests and can at least offer appropriate counsel about why one ought not allow oneself to be controlled by this desire and how one might try to deal with it in a good way. As Hans Urs Cardinal von Balthasar said, "success" is not one of God's names, but "consuming fire" is.[26] This is, I think, in general how we should deal with concerns that our efforts to transform our culture (in this case, the culture of medicine) might be unrealistic.

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[26]Hans Urs von Balthasar, *Razing the Bastions* (San Francisco CA: Ignatius, 1993), p. 46.