

Dying with Others

Reflections on Ataxia, Desperation, and Ken's Mom

In memory of Shirley "Mubster" Yen Hsu, who passed from this world into the communion of saints on October 7, 2006

Abstract: The author employs Thomas Aquinas's conception of divine existence in order to characterize creaturely being as contingent rather than necessary, and suffering as participatory rather than isolating. In this way, the article disputes both the narratives of necessity inherent within medical appropriations of immanent causality and the views of suffering that warrant practices of technological desperation. The author relates the story of one family's illness, through interspersed eulogy, and highlights how technological mastery imposes indictments of ethical "responsibility." The author concludes by showing how baptism and the Eucharist offer narratives that might resist such imposition.

It's funny how death compels us to see the small things in life that we so often take for granted. Of course, for my mom those were the very things she had the most trouble with—the seemingly trivial things that we don't think twice about, like walking, talking, writing, eating, drinking. For as long as I can tell, ever since I was a little child, that's what I remember. I remember my mom had a hard time doing the little things.

On Saturday, October 7, 2006, Ken's mom died. For almost thirty years she suffered from a particularly cruel version of ataxia. Ataxia, which comes from the Greek, means, harmlessly enough, "lacking in coordination." Yet the rather innocuous-sounding etymology does not give the disease its due. Spinocerebellar ataxia is a degenerative disease that affects the body's nervous system, slowly working from the outside in. There is first the loss of sensation in one's fingertips, then loss of general balance, and eventually destruction of one's ability to talk, see, and swallow.

Cat Jonathan Tran is assistant professor of theological ethics in the department of religion at Baylor University, Waco, Texas. His book on the Vietnam War, theology, and memory is forthcoming in Blackwell's series Challenges in Contemporary Theology.

At first it was her balance. She would begin to stagger a bit when she walked. Sometimes she would run into walls or occasionally stumble and fall to the floor. I later learned that it was shortly after she gave birth to me, when she was in her early forties, that the first symptoms began to show. . . . In having to live with this disease, my mom knew fears that many of us will never have to know. She was completely aware of everything that was happening to her. She saw her body deteriorate more and more as the years went by, and there was nothing she could do about it.

In the end, the disease incapacitates the most rudimentary functions: Ken's mom died from pneumonia, probably caused by an inability to swallow properly something she had for lunch. Though it has a variety of symptoms and severities, in the worst cases ataxia culminates in a gnostic nightmare: a soul and mind encased in a bodily prison, fully conscious yet surrounded by darkness, silence, and memory of a life locked outside.

Drawing on Thomas Aquinas's conception of divine and creaturely existence and the Christian practices of baptism and Eucharist, and both as displayed in Ken's eulogy (from where these interspersed quotes are taken), I reflect on Ken's mom, Ken's potential for ataxia, and bioethical issues such as genetic mapping, death and dying, responsibility, and the narrative structure of existence. Ken's mom's story is sad. Because ataxia can be inherited, Ken's story may also end sadly. Yet I want to ask whether their stories are *necessarily* sad and how God's life as self-giving between Father, Son, and Holy Spirit, a life in which we participate through baptism and Eucharist, might help us better story our lives in light of what Ken's eulogy calls the "communion of saints."

At the beginning of the semester I asked the graduate and undergraduate students in my bioethics seminar about Ken. Through recent advances in genetic mapping, Ken can find out with fair certainty whether or not he will develop ataxia. Yet, regardless of the diagnosis, there is no known treatment for this disease. And therein lies the rub. Since Ken *can* find out, *should* he, considering the absence of a cure? Knowing that he has the potential for inheriting his mother's ataxia, does Ken have a moral obligation to test for the disease? Specifically, considering the huge financial strain that medical dependents exert, should Ken at the age of twenty-nine find out whether he will develop ataxia? More specifically, having recently become engaged, does Ken have a responsibility for letting his fiancée Janet know into what kind of life she is entering? Does the genetic configuration of ataxia fate Ken and Janet to reproductive technologies, themselves ethically ambiguous? The capabilities made possible by genetic testing increase the demands of responsibility; that Ken *can* find out, that Janet *can*

choose, magnifies potential indictments of irresponsibility. (If a person could not possibly know, if genetic testing could not do what it can now do, such contingencies as ataxia would simply be seen *as* contingencies, in common parlance, “bad luck,” warranting societal sympathy rather than admonishing individual responsibility.) My students went back and forth, some opining one’s obligation to society and the ever-increasing burden of Medicare, others firing back about the unconditionality of love and Janet’s right to choose. It was an impossible question, of course, made easier only by the reality that we were talking in sanitized hypotheticals unaffected by the day-to-day realities of ataxia.

Immanent Causality versus Suspended Gifts

In my class’s discussion of Ken, Ken’s mom, ataxia, and the question “Since Ken *can*, *should* he?” or more precisely, “Since Ken *can*, *shouldn’t* he?” we did not consider two things: first, whether the diagnosis was correct, and second, the meaning of the diagnosis itself. As to the first, does a genetic prognosis that Ken will get the disease mean that he *will* get the disease? My suggestion that a genetic confirmation does not necessarily mean that Ken will develop ataxia will surely strike some as absurd, for certainly science relies on the ontological realities of immanent and necessary causality. If one’s genetics predict one will get the disease, then one will get the disease as surely as cause precedes effect. To deny the logic of causality is to deny the very mechanics that make up our lives as physical beings. However, let me press my question by posing it conversely: Just because genetic screening confirms that Ken *will not* develop ataxia, does that mean that Ken *will not* develop the disorder?” Along with hereditary ataxia, there is something known as “sporadic ataxia,” which is a nonhereditary form of the disease. In other words, Ken may not have genetic ataxia but may still develop sporadic ataxia. I bring up sporadic ataxia not to blur the distinction between a disease’s hereditary and nonhereditary tendencies. Rather, I want to suggest that immanent causality, especially as an ontology that emanates in the practice of genetic mapping as a cartography of humanness, imposes narratives of necessity and practices of desperation that run counter to a Christian theology of gift. That is, neither do we exist by necessity nor are our lives determined by the course of necessity and its attending disciplines.

According to Thomas Aquinas’s classic conception of God, God’s being or “essence” is such that God’s being *is* God’s existence. God is the one who *has* to exist by the very condition of *being* God: “God is not only his own essence . . . but is also his own existence.” By contrast, humans as creatures do

not *have to* exist. To be a creature, that is, to be *created*, is such that one's being is not of necessity to exist; instead, one exists *contingently*, namely, by another's creative activity: "Therefore that thing, whose existence differs from its essence, must have its existence caused by another." Our condition as creatures is that we exist, but we could as likely not exist; that is what it conditionally means *to be* a creature. The distinction between God and creatures is that whereas God by his nature has to exist, we by our nature can or cannot exist; our existence depends on God.¹ In this way creaturely existence is dependent on the divine: "'In him, we live and move and have our being'" (Acts 17:28).² Following Thomas's doctrine of divine simplicity, since God is eternal "pure act," creatures, to the extent that they exist, exist *in* God, and to the extent that they have being, receive being *from* God, "being by participation" according to Thomas. Existence, at every moment, remains dependent on God, to whom the entirety of the creature's life is suspended; there is no moment when the creature exists independently, nor any moment when her life unfolds autonomously; every moment and every unfolding take place in the divine life, where Father, Son, and Holy Spirit eternally give themselves to themselves. In this self-giving (*kenosis*) the divine will overflows toward the abundance of creation. Immanent existence ensues by participation as God continuously draws the creature toward the end that she desires (*ex convenientia*), the desire for the beauty that is her life in God. Though the creature need not exist, to the extent that she does exist (and this is the force of Thomas's claim), she exists as participating in the divine life. In this way, to be a creature *qua* creature is to survive *at every moment* by way of divine donation, that is, gift.

This account of gift runs counter to the narrative of immanent causality. To exact that creatures *must* exist *at all* or *in any particular way* is to undermine creaturely contingency, to ignore that creatures are created. To demand a particular mode of existence, say a life free of ataxia, is to deny that one lives suspended to

1. Under "The Simplicity of God" in the third question through two articles, "Whether God Is the Same as His Essence or Nature?" and "Whether Essence and Existence Are the Same in God," in the *prima pars* Thomas delineates God's being and God's existence. *Summa Theologica*, I.Q.3.a.3–4, trans. Fathers of the English Dominican Province (Allen, TX: Thomas More Press, 1948). In *On Being and Essence* Thomas writes, "It follows that everything whose being is distinct from its nature must have being from another. And because everything that exists through another is reduced to that which exists through itself as to its first cause, there must be a reality that is the cause of being or all other things, because it is pure being." Trans. Armand Maurer (Toronto: Pontifical Institute of Medieval Studies, 1968), IV, 7. I am indebted to Jeremy Stirn, who directed me to this latter text.

2. See John Milbank and Catherine Pickstock, *Truth in Aquinas* (London: Routledge, 2001), and Pickstock's essay, "Suspending the Material: The Turn of Radical Orthodoxy," in *Radical Orthodoxy: A New Theology* (London: Routledge, 1999).

the divine goodwill. To assume that one's life is predetermined by anything other than God is to deny God's providence over history, exactly to the extent that history and time occur within God's eternal life. And to tie God's eternal freedom on account of any one determinate in time, such as a genetic map, is to seek to suspend God's freedom to something other than God. God may by God's freedom so will that an individual's life unfolds as mapped in that individual's genetic code, yet God is not determined by that code. Nothing and no one can map God's will other than God.³ In other words, Ken may test positive for genetic ataxia and never develop ataxia. Likewise, he may test negative for genetic ataxia and yet develop sporadic ataxia. Just as well, Ken may not have genetic ataxia or develop sporadic ataxia and yet may step out of the genetic screening clinic and be killed by a runaway car. All of these are possibilities. Denying these possibilities by relegating them to the "miraculous" is to forget that every moment is given as gift, that nothing can be presumed.

The problem with the question "Since Ken *can* find out, *shouldn't* he?" is that it rests claims of "responsibility" and moral obligation upon a causal rather than a contingent presumption of existence. The fact that none of my students thought to question the question shows how narratives of causality ensue as totalities, which "story" us and thus determine our lives. The power of such stories is that they, like divine simplicity, imagine no outside and thus want to be like God. Thomas appropriated Aristotle's causality in terms of creative contingency because he knew that without a Christian account of creation there is only linear causality and Stoic fatedness.⁴

To live in the world of science and modern medicine, in a sense to be a patient, is often to live one's life not as gift but as predestined by something

3. Pickstock elucidates an important subtlety here: "While according to the bare logic of his omnipotence, God could have redeemed us another way, the aesthetic fittingness of the way actually chosen reflects the way in which the eternal divine Logos itself, in its free compulsion and compelled freedom, is most adequately characterized as the eminent realization of beautiful *proportio*. Hence the means appointed, in the very freedom (aesthetically compelled) of this appointment, manifest the heart of divine 'necessity'" (Pickstock, *Truth in Aquinas*, 63). Although God is free to do anything, God does that which is *fitting* to who God is in God's self, which is to say, God did not need to become human, as Anselm argued, yet the Incarnation limns who God always is such that the mission of the second person of the Trinity would *always* look like the Incarnation. Thus, while God orders the creation by certain realities, such as immanent causality, that order, rather than governing God's freedom, displays God's beauty. The category of beauty is clarifying here because aesthetics obviates conceptualizing God's activity on mechanistic frameworks. If there is "necessity" in God, it is that which floats between compulsion and sheer arbitrariness, an aesthetics Pickstock terms "fittingness." Understanding humanness and biological eventualities such as genetic predispositions through filiations of beauty diminishes positing divine freedom as encroachment upon freestanding systems.

4. *ST* I.Q.2.a.2.

other than God. Think here of what happens in hospitals. When a patient gets a dire diagnosis, say of a terminal illness, the doctor speaks the language of immanent causality dressed up in clinical garb: “The cancer *will* begin in your lungs and *then* will metastasize and *then* will spread to your brain and *then* will . . . Of course, we have the option of *aggressive* chemotherapy, which *will* arrest the cancer’s development and *then* will . . .” Stuck within the limits of necessary causality (and think here of Wittgenstein’s dictum, “The limits of your language are the limits of your world”), the patient foists divine *intervention*, divinity truncated within the terms set forth by the harsh reality of cause and effect (“Oh God, please let the chemotherapy work”). God here plays at best a secondary role, a role in the gaps of the cold, facts-driven “real world”—a world that determines creation *and* God.⁵ Since medical prognoses, based on practices such as genetic screening, indicate at most *probability* rather than *certainty*, God, such thinking avers, still has room to operate in the gap between probability and certainty. Such a view of God implies that God, like creatures, is suspended in the interstice between cause and effect, attempting to muster as much “miraculous” interference as divinely possible. Rather, God suspends probability and certainty in the sense both of upholding and interrupting their causal logic. The very promise of creation *ex nihilo* means that God can work through particularities (causality, genetic predispositions, skillful doctors, chemotherapy, and the like) but is not determined by them. Metaphysically, the only way to resist totalizing narratives such as immanent causality is by way of counternarrative; Thomas’s conception of gift offers us this alternative and thus illumines the hubris of “pure” immanence. This is not

5. One might recall here Reinhold Niebuhr’s Christian “realism,” which had more to do with a sociological reworking of original sin than an allegiance to a scientifically based facts/values distinction. Still, Niebuhr’s architectonics is at work anytime Christian eschatology is supplanted by the tragic. Niebuhr’s ethics of tragedy and its mandates for “responsibility” finds its origin in a certain Lutheran reading of Augustine’s two cities and its bioethical articulation in Paul Ramsey’s *Fabricated Man* (New Haven, CT: Yale University Press, 1970). Counterassertions of a higher “ideal” can never defeat realism because idealisms, especially in their Protestant liberal forms, as Niebuhr famously demonstrated, are unable to anticipate and overcome such realities as Auschwitz. Instead, Christians can only point to realisms Niebuhr declined, such as Chalcedonian affirmations of Christ’s *real* humanity and *real* divinity. In his rejection of liberal pacifism Niebuhr refused creedal christology, and in this sense he understood better than most exactly what was at stake in Christian realism: “[Pacifists] do not understand that the perfect love of Christ comes into the world, but that it does not maintain itself there; that the cross therefore stands at the edge of history, and not squarely in history; and that Christian faith has quite rightly seen in this cross a revelation of the nature of the divine and eternal as well as of the ultimate historical possibility and impossibility” (D. B. Robertson, ed., *Love and Justice: Selections from the Shorter Writings of Reinhold Niebuhr* [Louisville, KY: Westminster/John Knox, 1992], 276). In this essay I offer a participatory and doxological account of Christ’s humanity and divinity in terms of baptism and the Eucharist.

to say that genetic mapping does not have its uses and resulting therapeutic interventions; however, those uses must be envisaged and practiced within something like a trinitarian ontology of gift if they are to avoid entrapping humanness within a horizon of its own materiality.⁶

Performing the Sacraments

The second element of the question “Since Ken *can* find out, *shouldn’t* he?” my students never questioned was the meaning of Ken’s mom’s life, or more specifically, the meaning of suffering itself. The rationale for genetic mapping is precisely to stave off possibilities like ataxia’s suffering, to presage genetically and, if possible, manipulate suffering. In other words, part of the goal of genetic mapping is to occlude the possibility that anyone, including Ken, would ever end up like Ken’s mom.

When we were cleaning out her place last weekend we found a draft of an old letter she had sent to Cal State San Marcos seeking employment there. She wrote, “I am a 54 years old disable woman suffer from ataxia and have to using a walker to walk. I have several years of pharmaceutical experience in the identification of drugs. . . . I also did a lot of methods development work for identifying those drugs. Thank you very much for your time and attention. I am looking forward to hearing from you.” The letter was littered with misspelled words and grammatical errors, but it was all she could manage in her condition typing on an old typewriter. It saddened me to think how my mom must have waited and waited for a reply but no reply ever came. Later that night I told Janet how scary it must have been for her to have reached the point where she could no longer support herself and how lonely she must have felt.

6. This article approximates John Milbank’s “outnarrating” mode of engagement in *Theology and Social Theory: Beyond Secular Reason* (Oxford: Blackwell, 1990). Samuel Wells extends and corrects Milbank’s “outnarrating” by way of “overaccepting.” By placing the locale of Christian ethics historically within the fourth act of Hans Urs von Balthasar’s five-act “theo-drama,” Wells shapes ethics eschatologically in terms of human participation in the divine drama of redemption. Wells understands “overaccepting” as coming around (rather than against, which he terms “blocking”) the stumbling childlike errors and embarrassments of privation and “weav[ing] a wonderful melody . . . to receive them as gift, to overaccept” (Wells, *Improvisation: The Drama of Christian Ethics* [Grand Rapids: Brazos, 2004], 132). In the same way that this paper attempts to overcome desperation and mastery by an analogical account of creation as gift, so Wells shows how the goods of bodies, death, and dying and technologies such as cloning cannot be understood outside the whole Christian drama of redemption. As Stanley Hauerwas has taught me, Christian accounts of creaturely origins require eschatological lenses, for it is only by seeing what God will do that we can understand what God has done. The strength of Wells’s *Improvisation* is that it imagines the eschatological as something God has *already* done, in turn making certain impossibilities quite real.

Such suffering is surely terrible, and one should do all that is ethically feasible to eradicate its possibility. Whether measures are *desperate* or not usually depends on how determined one is to preclude certain realities, desperation intensified by an ostensibly definite immanent causality. In the case of the terrors of severe ataxia, almost no one would regret ending its possibility—except Ken and Ken’s mom.

To end ataxia, to eradicate it, is to eradicate the person so afflicted, for there is no ataxia except its instantiation in a certain person. Even if it exists only as a genetic predisposition, it is not something that can be outside of being constitutively human. Ultimately, what ataxia and all such disorders are is a potential side effect of being human, of being a created and suspended being. To be human is to live with the possibility that ataxia may set on at any moment. Thus, we must step back and wonder how else we might conceive ataxia specifically and humanness and suffering generally. In other words, might there be a way of thinking about human suffering that does not end in desperation?

My mom’s only hope perhaps was a miraculous healing. I think that’s what initially led her to Christianity. All the traditional avenues had been explored and they had all come up empty. Maybe it was time to give faith a try. So she started going to church. But a miraculous healing never came. She didn’t get better. Her balance never improved. Her speech worsened. Her muscle coordination continued to deteriorate. Yet as the disease kept on taking its toll on her, she kept going to church. And as the years went by it seemed that my mom had gotten to a point where she no longer felt sorry for herself. In the past ten years, visiting and caring for her the best that I knew how, I never heard my mom complain about what she was going through, not even once. I never heard her whine or grumble or get down about her lot in life. Even with everything that was happening she never railed at God in resentment. Some may call it naive or perhaps stubborn or just plain stupid. But I think my mom learned something that others might not know. I think my mom understood more deeply and more fully than most just what the scriptures mean when they say that God “is able to accomplish abundantly far more than all we can ask or imagine” (Eph 3:20). My mom’s life is not one we would ask for or even want to imagine. And yet there is in her life a glimmer of beauty that I cannot yet fully understand. Somehow in my mom’s fragile and broken body I have seen God bring forth the miraculous in a way I could not imagine, because I never knew what the miraculous could be. Hers was not a life we would ask for or even imagine, but she was given to us as a gift from a God who is able to accomplish abundantly more than all we ask or imagine.

If the meaning of suffering is such that it warrants desperation, then the mastery of nature is not only desirable but is morally responsible. Mastery would then be a good, and desperation would simply name “what drives us.” However, if the meaning of suffering can be narrated beyond desperation, then mastery may begin to look not like “responsibility” but rather idolatry and impatience.

As Christians, Ken and Ken’s mom understood themselves within the Christian narrative. As such, they were able to understand her suffering beyond the question of theodicy. Specifically, baptism and Eucharist had engrafted them into God’s story, “being by participation” as we saw in Thomas. At baptism, Ken and Ken’s mom were baptized into Jesus’ very body, a body that was Jewish, that suffered, and that was given for the world. In that, their bodies were no longer their own but belonged, along with other bodies, to the one gathered body of Christ, who proleptically restores all bodies to their ends. Once this occurred it became incoherent to speak of Ken’s mom’s sufferings as hers alone to bear. Sacramentally, Ken’s mom’s sufferings became Ken’s. More precisely, at baptism, according to Paul, Ken’s mom’s sufferings became Christ’s suffering, in which Ken now took part as a member of the gathered body. Participating in such suffering is not only imaginable, but according to the apostle Paul, it is desirable “to know Christ and the power of his resurrection and the sharing of his sufferings” (Phil 3:10). Through Christ, Ken was now “found” in his mother’s sufferings; through sufferings received eucharistically, he now shared in his mother’s sufferings, just as every baptized person shares in this communion. Likewise, Ken’s mom’s devastated body is “found” in the whole body’s faculties; in the gathered body’s talking, seeing, and swallowing is her talking and being heard, seeing and being seen, and enjoying and being enjoyed. “If one member [of the body] suffers, all suffer together with it; if one member is honored, all rejoice together with it” (1 Cor 12:26). This also means, whether or not Janet married Ken, as a baptized person she too shares in Ken’s present and future sufferings and joys, ataxia or not. For Paul, and the baptized, such sharing is not to be avoided; indeed, it is to be desired, for in such moments we “know Christ and the power of his resurrection and the sharing of his suffering.” At baptism, Christians join an incredible set of performances, performances instantiated again and again at the celebration of the Eucharist, where the presence of Christ and his performance of faith gather the body into the one broken and suffering body. At the celebration of the Supper, Christians *enact*, “This is my body, given for you,” and are inculcated into the *performance* of gathered bodies.

For as long as I have known Ken, he had gone nearly every other day to be with his mom. Because his family could not do it, it was left to Ken to care for his mother. And so her sufferings became his own, performatively drawing him into the life of God. Visit after visit, month after month, year after year, Ken went and suffered with his mother. He fed her, cleaned her, read to her, held her hand, rolled her wheelchair. He brought all manner of entertainment, a computer through which she might communicate, and a steady flow of Chinese food—no matter how much it smelled up the ward! In the end, Ken was the only person in the world who could understand her, and it was on him that she depended; he became her hearing, talking, and tasting. Ken's mom's life became his own.

Paul writes further, "For his sake I have suffered the loss of all things, and I regard them as rubbish, in order that I may gain Christ and be found in him, . . . if somehow I may attain the resurrection from the dead" (Phil 3:8–9, 11). Ken's life with his mom proclaims, "Resurrection!" for what else makes such a life possible? It reminds us that suffering—though horrible, unimaginable, and undesirable—is the life Jesus chose. And it is the life he chose for those who would follow. At the final resurrection, though called the Lion of Judah, Christ appears as the slaughtered Lamb, still bearing the marks of our transgressions (Rev 5). Though he is the eternally begotten Son, the second person of the Holy Trinity, and the Word of God, he comes suffering; that is the life he has chosen and the life that we receive through the bread and the cup. The fulfillment of all things does not give meaning to suffering but rather shows us that those who suspend their lives to the suffering find themselves present among those who sing, "Great and amazing are your deeds, Lord God the Almighty!" (Rev 15:3).⁷ We join, with Ken and all the saints, a life where suffering is not only an imaginable story for us but where it is the story of God, a story into which we are baptized and a story in which we partake at the Eucharist. Desperation and mastery play no part in that story, and they play no part in Ken's mom's or Ken's or Ken's *wife* Janet's story precisely because they find themselves engrafted into God's story, a story of gift displayed on a Friday, a Saturday, and a Sunday, a story that overcomes and even suspends the necessity of both desperation and mastery.

*When we speak of saints, we often think of those who lived perfect lives,
whose lives were lived far above and beyond the scope of typical everyday*

7. Only as he reaches paradise, nearing the beatific vision, can Dante utter, "*E'n la sua volontade e nostra pace*" ("In his will is our peace") (*Purgatorio* 3.85).

living. If that's what a saint is, then my mom certainly isn't one. She wasn't perfect—she was known to have a bitter temper, and her stubbornness was at times infuriating. Far from living above and beyond the typical, everyday life, my mom couldn't even walk, and it was a struggle for her just to eat and drink and talk. My mom's life was consumed with just trying to get a handle on day-to-day living. And so it is in remembering my mom's life that I am reminded of the way in which it is in the midst of the ordinary, everyday things of life that God's miracles are often to be found. And I think that's what saints do best. I think saints are better understood as those who lived lives that help us to see the goodness of God, to sense the presence of God's hand even in the most desperate and trying of circumstances. I think that's what my mom helped me to see and perhaps some of you as well. And so it is that she now takes her place among the communion of saints in gathering around the throne of the one who alone is worthy of praise. Amen.⁸

8. I thank Ken Hsu for graciously allowing me to incorporate his eulogy and to tell his and his mother's story, however inadequately.



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