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Hoping, Willing, and Narrative Re-Envisioning¹

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Abstract

At first glance, hoping and willing do not seem to have much to do with one another. They evoke quite disparate turns of mind, in fact. Hope, which Aristotle called a "waking dream," is associated with imagination, daydreams, and wishful thinking. Willing, on the other hand, is aligned with practical effort, discipline, and acting against one's inclinations. Despite their lack of obvious affinity, in some communities—especially in the face of extreme suffering—the two acts may develop a close kinship. Hope as a moral task, even a narrative quest, can demand the arduous cultivation of the will. Hope is not necessarily something people easily acquire—not a matter of mere wishful thinking when life becomes difficult, but a difficult moral obligation that must be assumed as a way to confront pain and despair.

Hoping and Willing in Ethnographic Context

Since January 1997, a group of primarily anthropologists and occupational therapists, including myself, has conducted a longitudinal ethnography of African-American families who have children with serious and chronic illnesses or disabilities. Through the years, we have come to know the ebbs and flows of chronic illness and to witness what such illness means in the neverending process of negotiating health care with shifting casts of health professionals and changing bureaucratic processes. We accompany families to clinical visits, observe, and—where we are allowed—videotape such visits, and separately interview participants about what they perceived happened in their healthcare encounters. We also observe and videotape children and families at home and in the community, especially at key family events. We have been to many hospital events, but also to birthday parties, drill team parades, christenings, and funerals. This kind of longitudinal design has revealed a great deal about clinical encounters as events in family lives and about multiple perspectives between families and clinicians as these develop and change over time. It has also illuminated how interwoven hoping and willing can be for people who must learn to face suffering as part of daily life.

The families in our study frequently speak of the importance of finding a way to hope in the face of despair, of being a "good parent" to their children. They also speak of needing *strength* in order to hope. When they find themselves in a despairing place, they pray for "strength" to "hang in" with their children, to not "give up" even when the prognosis looks grim. Hope is necessary for their children's recovery or, at least, for easing the pain. This sometimes creates conflict between families and clinicians. While the battle metaphor is often used in talking about the treatment of a disease in American parlance (for example, the "fight against cancer"), clinical encounters themselves often become battle-like, particularly over the negotiation of hope. In one family the parents refused to give up on their critically ill infant,

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who lived most of her eighteen-month life in a neonatal intensive care unit. As her father stated firmly.

The doctors would say, "Bring the whole family up here. She's going to die. This is her last day." You know, we fed off of that.... They told us...that baby ain't going nowhere. It's amazing, you know? You listen to them doctors, and then you get scared.... They tell us all the time that she's gonna die. But we fight. We hang in there with her. We hang in there.

These parents hoped in a way that ran counter to medical prognoses; the clinicians presumed that their insistence on hope was a form of denial. Contrarily, from the parents' point of view, hoping depended heavily on cultivating "strength" or will.

In what sense is the insistence on hope connected to will? How does it assume the role of a moral burden that requires immense strength to shoulder? One mother, Barbara, had a little girl named Rhonda who was diagnosed at three with a malignant brain tumor. Barbara described how she dealt with this: "If I lose hope, then I lose focus. *If* I do. I just think positive every day. And pray that a miracle is coming. And that's it."

It has become clear in our research that such parental declarations as Barbara's represent not a simple clinging to illusion but a very deep and difficult moral battle. I met Barbara just a month after her daughter's initial diagnosis of cancer, and she recounted the experience of hearing the prognosis. When a doctor stated that her daughter had the "highest-risk kind" of cancer, she was stunned. She recalled the unreality of it. She told herself over and over, "I'm dreaming. I'm dreaming. I'm dreaming. I'm dreaming on TV."

A year and many interviews later, she was ready to talk more openly about that early period and her own devastation. "I was crazy with this situation in the beginning," she said, admitting that she had even been contemplating suicide. "And, in the beginning I had said, 'Well, if something happens to my daughter,' I said, 'If she don't make it, I'm not gonna make it either.' I was saying that I'm gonna kill myself if my baby ain't gonna make it. And I meant that." In confronting this immense despair, she determined to set herself the task of cultivating the will to hope not only for her daughter's recovery but for her own courage to bear whatever befell her child. She prayed for strength. While she described this as praying for a miracle, it is important to note that her hope was not simply for a cure. The task of hoping involved a much more subtle project. She struggled to be able to find hope even for things that would once have left her stricken. She came to cherish smaller miracles. When her daughter fell into a coma, the doctors told her that her daughter would never wake up. Barbara felt she needed to speak to her daughter "one last time," and this was what she prayed for. When her daughter did, quite unexpectedly, awaken from this coma, Barbara experienced this as an answered prayer, a moment of hope and healing. This can be heard in the story she tells of this moment of awakening:

The doctors were telling me...she's not going to make it out of this. It's just a matter of time. She's going to die. And why don't I save her the agony and just let them disconnect [life support]? I said, "Don't ask me to do this. To take her life. I could never live with myself if I did that. I said, I told them that if God, if God wants to do it, then he can do it.... I just kept praying to God not to let this happen. I just told Him that I wanted to talk to her one more time. And then Rhonda...she snatched [the breathing tube] out herself. And she started breathing again and everything.... God, he answered my prayers and everything. He let me talk with her one more time.

This mother's transformation in how to experience hope came through most powerfully in the funeral speech she gave at her daughter's memorial. She spoke of how her "little girl fought hard for so long." But, she told the audience, it wasn't the "doctor's call" or "her call." Rather,

as she put it, it was "God's call." She speaks of this "call," for which she lost her child, as something she has learned to be grateful for: "And I'm so grateful that my baby's in heaven,' cause I know she's there right now. [Audience: Amen.] I have no regrets. You know,' cause she did everything she needed to do, and everything she wanted to do in her whole lifetime."

As these quotes underscore, hope is not a simple "denial" of reality, but something that is painstakingly cultivated. Part of the struggle for hope involves a shift of perception in light of changing circumstances. Having the capacity to hope depends upon a person's willingness to undergo a difficult journey, even a personal transformation. This journey may even manifest itself in experiencing the death of one's loved child *not* as bitter betrayal but as the culmination of a life fully lived. It is unsurprising that such an arduous journey demands "strength." This picture of hope may require imagination, but it is far from a numbed blindness to the hardships of reality or an insistence on living in dreams instead of "facing facts." Notably, the connection of hope to the capacity to act in the face of suffering is a topic that has provoked some important theoretical consideration.²

Rethinking the Concept of Willing

From a Western perspective, in common parlance and philosophy, willing tends to mean "choosing to act" in some particular way. There is an emphasis on a moment of choice and, sometimes in difficult situations, on the deliberation that surrounds that choice, as well as an emphasis on doing something—a connection between motive and some kind of public action. ³ The connection of willing to action is especially consequential when it comes to moral choice. In general, philosophers have presumed that decisions do not count as willing something if they are only privately made, as willing results in observable action. The will has also been linked to morality—the capacity, or one might say "willingness," to make moral choices.

This picture of willing as a *moment of deliberate choice* is problematic in making sense of the way willing works among African-American families of chronically ill children. Parenting kin agonize over what they ought to do and how best to care for their children. As I have underscored, their concerns are explicitly or obliquely connected to the problem of how to have the *strength* to do the right thing. This "strength" is conceived as a kind of will power, the power to do what is right even against inclinations to follow an easier path—to not bother with the exercises the physical therapist has prescribed, to skip a doctor's appointment that requires a three-hour bus ride with a disabled child, to resume drug habits and leave their child for another family member to tend.

Such crucial moral issues may involve moments of choice, but this task of willing the "right thing" involves much more than choosing—and acting—well in discrete moments. Parenting kin may, for example, criticize themselves for not always being strong enough to care for their children as they should. They talk about getting "tired," even "so tired" but having to "go on anyway," underscoring how much will power is involved in living good lives, being good parents, and simply facing the daily trials that poverty, racism, and serious illness inflict. They speak about finding the will to keep going when life is grim, to hope in the face of despair. In short, will is required if one is to be able to hope. Moral choice, moral change, and moral

²For example, Ernst Bloch's *The Principle of Hope*, vols. 1—3 (1986; Cambridge: MIT Press, 1995) constitutes a seminal work that situates hope as a serious topic of theoretical inquiry. A number of thinkers have followed. See Henri Desroche's *The Sociology of Hope* (Boston: Routledge & Kegan Paul, 1979); Vincent Crapanzano's *Imaginative Horizons: An Essay in Literary-Philosophical Anthropology* (Chicago: University of Chicago Press, 2004); and Hirokazu Miyazaki's *The Method of Hope: Anthropology, Philosophy, and Fijian Knowledge* (Stanford: Stanford University Press, 2004).

³Charles Taylor argues that the link between will and morality (especially morality defined as transformation of the will) was introduced

³Charles Taylor argues that the link between will and morality (especially morality defined as transformation of the will) was introduced into Western thought primarily through Christianity, but that this connection has gone through various secularizing transitions and, in its secular guises, remains one of the most powerful ethical precepts in Western thought. See *Sources of the Self: The Making of Modern Identity* (Cambridge, MA: Harvard University Press, 1989) 22.

achievement are fundamental and often voiced concerns in this African-American community. They are inevitably connected to selves in the process of becoming—selves created in community rather than solo achievements.

I want to offer a different picture of the will that speaks in a better way to the dilemmas and struggles these African-American families express and to their conception of the will—especially as captured by the notion of garnering "strength" to do the "right thing." Because the "moral will" is of such concern to these families, I concentrate on willing as it is specifically tied to moral action.

There are four features intrinsic to this alternative conception of the will. First, moral willing is a refocusing of attention, rather than a choice made at a discrete decision point. Second, the "doing" connected to moral willing is as likely to be directed toward internal re-orientation as toward external action—toward "emotion work," cultivating and maintaining hope. Third, such doing requires a concept of action that is not atomistic but narrative. And fourth, a concept of moral willing cannot be disconnected from a notion of self, a both social (created in community) and narrative self.

Moral Willing in Ethnographic Context

To examine these four features of moral willing, I now turn to one of the cases in our study.⁵

Sonya is a woman whose son Gus was terribly burned in a household accident seven years ago, when he was just a little more than a year old. Sonya and Gus live with Sonya's mother, Doreen; one of Sonya's older sisters, Mary; and Mary's four children. Sonya and Mary are the last two of ten children. Sonya, who is now twenty-seven, has always lived at home, and theirs has been a close-knit, multi-generational household.

I met Gus and his mother just a few months after the burn accident (in September 1999), though I had known the family since 1997 because one of Mary's children was initially enrolled in our study due to congenital hip problems.

The burn incident occurred in the kitchen. Gus was playing on the floor while his ten-year-old cousin Candace (one of Mary's girls) was cooking. She was supposed to be keeping an eye on him but didn't see when Gus suddenly reached up and tipped over a pan of burning grease onto his face. His grandmother Doreen immediately called 911 while they wrapped Gus in wet towels and waited for the paramedics. Sonya was not home when it happened.

Over the years the results of this terrible accident have presented Sonya with a number of moral challenges and choices. Should she allow Gus to have risky surgeries? Should she tell him how he got burned, that it was Candace who wasn't watching him? Should she talk to Candace about what happened? Should she let Gus go to burn camp, where he will be with other children who are burned and perhaps then see himself as somehow disabled, or a "burn survivor"? Should she make him wear the therapeutic masks and mouthpiece that he hates, though they may help to reduce scarring? When should she insist that he wear them, and when should she allow him to take them off? Should she be angry and blame Candace, or Mary and Doreen, who were all present when the accident happened? Should she blame herself?

While some of these practical and moral problems have required clear decisions that result in action, befitting the dominant notion of willing, these decisions have come only after significant

⁴This picture of the will has been heavily influenced by the moral philosophy of Iris Murdoch, Alasdair MacIntyre, and Charles Taylor. ⁵This case is based on interview data, field notes, and videotapes of home and hospital interactions. However, for the sake of brevity, here I rely heavily on several years of interviews with the mother, Sonya.

re-orientation of her emotions. She has had to struggle internally to make these decisions from a place of strength, from a "hopeful" place. Further, many of these moral dilemmas have no obvious action counterpart. Instead, they speak to Sonya's internal struggle to envision her world in what she deems the right, or most moral, way.

Re-Orientation versus Moment of Choice

In Western philosophy, the moment-of-choice model of willing has often been portrayed as a moment of freedom, an existentialist leap of "free choice." Iris Murdoch challenges this picture in several ways. She offers a counter example, where one decides to fall out of love with someone, which illustrates the first two features of moral willing—as a matter of orientation rather than moral choice, and as directed toward internal work rather than observable acts. "Where strong emotions of sexual love...are concerned, 'pure will' can usually achieve little. It is small use telling oneself, 'Stop being in love...." Willing is connected to a kind of emotion work in which one sets out to change oneself. As Murdoch notes, the commonly pictured "neo-Kantian existentialist 'will'" is a "principle of pure movement," a kind of leap in which one adopts one course of action rather than others. Such a conception is singularly unhelpful in describing what it is like for us to change. In thinking about how one faces the task of something like falling out of love, what she proposes instead is that a notion of willing be tied to something like learning, or what she terms "orientation." Willing so conceived is a matter of learning to shift attention, to re-orient, to re-envision and re-imagine.

How does this work in the case of Sonya? Occasionally she speaks in a language of clear moral choice that results in action. For instance, she has decided she will never tell Gus how the accident happened because she does not want him to blame his cousin who should have been watching out for him. "He don't know how he got burned and I vowed to never tell him that... because I don't ever want it to be, 'you did this to me." But such instances of discrete choices are rare. Situations that demand decisions must often be faced gradually, through both discussion with friends and family and heartfelt self-reflection. She describes in detail, for example, the agony she faced in agreeing that her son should have his initial surgery, a horror that never quite went away in later surgeries. "They [clinicians] told me all the bad things that could possibly happen. Like he could lose consciousness and die. You know, because we're paralyzing his body from the neck down with medicines.... They tell me that...his throat could swell while in surgery and cause him to lose his breath." Sonya herself had to fight the paralysis that comes with fear at these terrible possibilities: "I'm dealing with the idea that he got burned, and know that I have to deal with the fact that they might come out of this room and tell me that my son died."

She presents the problem of making the right decision not as a matter of willing something, of making a choice at a particular moment, so much as taking on the larger task of how to be the kind of person capable of facing such tough choices, acting from a position of hope. It is the

⁶The notion of willing has been identified with several binary oppositions: between objectivity and subjectivity, and between public meanings and private selves, determinism and freedom. These oppositions are supported by the common distinction drawn between reasoning and willing. Reasoning or thinking is conceived as an objective process dictated by concepts and rules that are necessarily public because they are grounded in language and other webs of social meaning. Willing, by contrast, is portrayed as a kind of private decision to act that is completely personal and subjective. As Murdoch puts it in her critical account of this line of argument: "Reasons are public reasons, rules are public rules. Reason and rule represent a sort of impersonal tyranny in relation to which however the personal will represents perfect freedom. The machinery is relentless, but until the moment of choice the agent is outside the machinery.... What I am 'objectively' is not under my control; logic [i.e., the public nature of meanings, rules, and reasons] and observers decide that. What I am 'subjectively' is a foot-loose, solitary, substanceless will. Personality dwindles to a point of pure will." See Iris Murdoch, *The Sovereignty of the Good* (London: Routledge & Kegan Paul, 1970) 16. She especially objects to a notion of agency that is confined only to these small moments of "free choice." "The agent," she writes, "thin as a needle, appears in the quick flash of the choosing will" (53). Instead, she argues the need for an agent imbued with history, in order to develop any adequate notion of willing, especially any adequate notion of the moral will.

cultivation of a particular way of being a mother for her son that she sees as her biggest task. She remarked once, plaintively, "Everyone would say you have to be strong for [Gus]. But, I mean, how do you, be strong, you know? It's like, that's like, that's my kid.... I'm vulnerable, you know what I mean? Because this is my kid and he has just suffered, you know, something I never imagined." Sonya is saying something about learning how to embody a different kind of will. In order to choose the surgeries from a place of strength, she must face her own vulnerability. Her portrayal of this experience echoes Iris Murdoch's notion of willing as "orientation," or, in this case, re-orientation.

In this community such re-orienting is almost never portrayed as an isolated individual affair. Undertaking the project of becoming strong for her son is a social project, one that involves her whole family for support and counsel. Sonya says, "My mom encouraged me [to agree to the surgery]. Mary [her sister] did too." Sonya recounts what they advised: "If it's best for him, then go ahead, and, you know, we'll deal with it.... Each step that we have to go through, we'll deal with it when we get there."

This "we-ness" of her account underscores how the whole family has been faced with the moral task of re-orientation. This is also evident in our interviews with Mary and Doreen. At first, Sonya says, this horrifying incident "crippled" the family: "When Gus got burned, it crippled us." But then things changed. The family "embraced" Gus and the pain of what happened; in fact, as the three mothers in this family have often said, this tragedy brought them together in a new way. They responded to it by learning to become stronger. All the children became involved with Gus's care. Everyone wanted to bathe him, to clean his wounds. Sonya describes it in this way:

As a family, we've never embraced anything, so when he got burned, it just like, everybody just grabbed it and hugged it and was like "this belongs to me." You know, even though it was like really hard and painful for all of us, but it, we had to deal with it as a family versus just me dealing with it as mom, or my mom dealing with it as grandmother. We just took it and dealt with it.

Re-Orientation as Internal Struggle

As both Murdoch's example of falling out of love and Sonya's situation imply, such reenvisioning or re-imagining is likely to involve internal struggles that are not necessarily (or primarily) manifest in changed outward acts. This, too, is something overlooked in descriptions of willing—the notion of struggle is curiously absent from philosophical discussions of the will, Murdoch notes. Willing to fall out of love involves not so much single moral choice or even a series of moral choices resulting in action, but a kind of practice, and one that involves significant internal work:

Deliberately falling out of love is not a jump of the will, it is the acquiring of new objects of attention and thus of new energies as a result of refocusing. The metaphor of orientation may indeed also cover moments when recognizable 'efforts of will' are made, but explicit efforts of will are only a part of the whole situation.⁸

Returning to Sonya, we can see that her efforts to make the right decisions also reveal that willing is frequently connected to a kind of emotion work in which one sets out to change oneself, to envision the world differently as a way to face tough situations and decisions as they arise. Willing here involves a change of heart, with overt, discrete acts of will as sporadic manifestations of this transformation. It was difficult for Sonya not to be angry at Candace, but she knew that her niece was not only "really, really sorry" but also felt horribly guilty. "She couldn't even, when I got to the hospital, she couldn't even look at me." In the hospital, Sonya

⁸Murdoch 56.

acts generously—she hugs her niece. But this generous act is only a moment in an on-going effort not to become bitter or blame anyone for what happened. This internal effort is at the heart of Sonya's many stories about caring for her child. Here is one of many quotes on the matter: "It was, oh God, so, so painful for me...' cause your first, I mean, you want to be mad. That's what I wanted to be initially. I wanted to be mad." She has had to struggle with this anger. "I tried really hard not to be angry, not to be bitter, because I know how it can make a person...." She is grateful that despite her anger, the feeling of hurt is what predominated. And even her hurt has gradually subsided. She has been able to move on, even to consider herself lucky for her child who has survived his surgeries and is "so, so smart." She couches this moral re-orientation in the language of healing. As she puts it, "I healed from my hurt."

Such healing, however internal, is also not a solo task. It involves many social practices and, as Sonya makes clear, it is aided by family and friends. Every time Gus has gone in for a surgery —and especially during the first surgery when he had a thirty-day hospital stay—he has been surrounded by his family and Sonya's friends from church, to the point of causing an overcrowding problem for hospital staff. These actions and the messages that Sonya received about how she should respond to her son's injury have helped her in getting over her anger. No one told her to "be mad," she remembers. Instead, "I had positive people around me the whole time," and they counseled her to "just think good thoughts and...what you think is what will happen."

Willing as Narrative Act

Willing, treated as a moment of choice out of which a specific action flows, especially fits an atomistic picture of action. Alasdair MacIntyre notes that this is a dominant conception of action, developed within analytic philosophy and existentialism but powerful also in sociological and psychological theories. In atomistic treatments, action is presumed to be something that can be broken down into simple and separable parts. In an atomistic frame one "analyse[s] complex actions and transactions in terms of simple components." 9

But if willing is a matter of orientation, this requires a different way of defining action itself. A contrasting view is essentially narrative. Rather than presuming that any particular action can be broken down into basic units, MacIntyre argues, action is only intelligible as embedded within larger contexts that are essentially narrative: "particular actions derive their character as parts of larger wholes." In everyday practical life, an act cannot understandably be isolated into the analytic philosopher's "basic action" but must be connected to these larger narrative contexts from which any particular act derives its intelligibility—in which it can be said to mean something. MacIntyre, who offers one of the clearest arguments on this point, puts it succinctly: "in successfully identifying and understanding what someone else is doing we always move towards placing a particular episode in the context of a set of narrative histories, histories both of the individuals concerned and of the settings in which they act and suffer." This is a fundamentally historical perspective, where particular actions derive their meaning from their place in a history or, more accurately, a number of histories. 12

⁹ Alasdair MacIntyre, *After Virtue: A Study in Moral Theory* (Notre Dame: University of Notre Dame Press, 1981) 190. 10 MacIntyre 190.

¹¹MacIntyre 197.

¹²MacIntyre gives several compelling examples of how necessary these broader contexts are. Suppose, he suggests, that a philosophy teacher comes to class, and instead of lecturing on Locke, he sets down a bowl into which he mixes eggs, flour, and sugar. His actions are understandable as "basic acts"—he is evidently baking a cake—but present a puzzle because they violate the context in which such acts acquire their intelligibility. To discover the meaning of his puzzling acts, his students will attempt to create stories that make sense of his bizarre behavior. Perhaps he is having a nervous breakdown? Perhaps he is trying a new lecture method, to involve the class in a new way (194–5)? Such puzzling, as Jerome Bruner has also forcefully pointed out, is essentially narrative in nature. See Bruner's Actual Minds, Possible Worlds (Cambridge, MA: Harvard University Press, 1986) and Acts of Meaning (Cambridge, MA: Harvard University Press, 1990).

If meaningful acts are narrative ones—that is, only intelligible as parts of unfolding narratives—then what does this say about willing? Consider willing as a narrative act. If willing involves, in many situations, the task of re-orientation, any specific moral choosing is understandable as part of a past and future from which this particular moment derives its (moral) meaning. That is, it becomes understandable as connected to an orientation that is part of a story—one that has its own history (say, falling in love with this particular, somehow unsuitable, man) and its own wished-for future (falling out of love with this man).

Obviously, such a history might be embedded within all kinds of larger social and personal narrative histories. There is no single correct narrative in which an action must be understood in order for it to be meaningful. Since many narrative contexts can reasonably be brought to bear in answering the question "What is she doing?" or "What is she willing?" how should one sort out just which narrative history should be given primacy as an answer? MacIntyre's answer is that we pay special attention to the "primary intentions" of the actor himself; how would he characterize his primary intentions in carrying out this task? This answer is likely too simple for the anthropological mind, but in selecting meaningful narrative frameworks for making sense of an action, there is something to be said for paying attention to what matters to the individuals one studies, even if this is not the only narrative frame one wishes to impose as part of the answer to "What is she doing?" or "What is she willing (to do)?"

Attention to the actor's personal perspective and concerns—as one critical starting point—is especially important if we are to build a picture of willing that gives some space for the agent's own view of his moral choices, moral dilemmas, and moral struggles. For willing, however it is defined, has carried with it a notion of some kind of directed intentionality, especially an intentionality that is at some level conscious to the actor, a deliberateness. I "will" to fall out of love with someone, and even if this does not materialize in an immediate change of heart, it directs a course of change that I undertake, a kind of personal project. Because of the deliberate and directed character of moral willing, a narrative conception of willing needs to be especially attentive to the conscious intentions and directed concerns of the agent.

The narrative nature of this moral willing, treated as moral re-envisioning, emerges in many ways in Sonya's dilemma. There are a number of narrative contexts that are invoked in the way this incident is interpreted by Sonya and her family. There is the narrative context of Gus, the person he is becoming, someone who is strong and smart, who can comfort his mother when she feels weak, who is not (according to Sonya) bothered by his scars, and therefore, through the way he sees himself, can teach her lessons about how to see him. He can teach her a hopeful stance. There is the narrative context of Sonya's own life story, a point to which I will return in the following section. And there is, of course, the family context. The whole process of re-orientation is given a narrative treatment in interviews with Sonya and other family members. There is the shift of the family from being "crippled" to "embracing" the pain of the accident, a process in which particular actions (or being willing to act), such as the cousins' insistence on helping to take care of Gus, take their (moral) meaning as episodes in an unfolding family story.

There are even future stories, told by some, that help Sonya by sketching a path that she, in the midst of her pain, could not see. For instance, a particularly close cousin and a "super Christian" spent a great deal of time with her when Gus was initially hurt. She offered her a hopeful future story that Sonya was gradually able to embrace, one that would take her from her initial anger and hurt to a place of belief and acceptance—a healing story. "She just talked to me about Jesus, and how God was gonna take care of it.... I just have to believe that it's gonna be OK, you know? Then, and then after that, that's when the process of healing will begin."

Sonya attempts to thwart some future stories through her actions, such as her vow not to tell Gus that it was Candace who was careless of him. Sonya does her part, as do other members of the family, to knit the family together in a closer way as a result of this accident, instead of letting it tear them apart.

Willing as Narrative Re-Envisioning of the Self

A narrative picture of moral willing connects re-orientation to a self in transformation. The connection of willing to a personal project of self-transformation has special salience for the African-American families I have followed, as they struggle with how to be good parents to seriously sick and disabled children. They very often link moral willing (or the ability to "act from strength," as they commonly express it) to a moral project of personal change. A primary narrative context is their own life history and the lives of those they care about, a point made by the "narrativist" moral philosophers. There is a need to connect what is "at stake" in any particular act to a narrative of the self, MacIntyre argues, because looking at only proximal intentions does not give us sufficient understanding of the meaning of an act. It does not lend enough depth. We need to know something about "longer and longest-term intentions...and how the shorter-term intentions are related to the longer." Longer-term intentions speak to a person's sense of self. This self is, for MacIntyre, a narrative one—in discerning what a person is up to by referring to their longer-term intentions "we are involved in writing a narrative history." 14

Charles Taylor builds upon MacIntyre's insight but in a reverse direction. It is not only that to understand what a person is doing (or willing), we must refer to various narrative contexts to decipher their intent. Taylor argues that it is primarily through having things "at stake" that one has a self at all. So, to speak of trying to understand what is at stake for actors is to speak of trying to understand who they are:

We are selves only in that certain issues matter for us. What I am as a self, my identity, is essentially defined by the way things have significance for me.... [W]e are only selves insofar as we move in a certain space of questions, as we seek and find an orientation to the good. 15

It is impossible to speak of understanding a person, Taylor continues, "in abstraction from his or her self-interpretations," and these self-interpretations concern what is of significance. ¹⁶ Moral willing speaks to our sense of what is significant, of what Taylor calls our "orientation to the good."

For Taylor, this orientation and the self constituted by it are essentially narrative. He further insists that this orientation only makes sense in light of a narratively understood self: "this sense of the good has to be woven into my understanding of my life as an unfolding story." Our self-identity is first and foremost built around morality—orientations to "the good," Taylor argues. Iris Murdoch calls us "moral pilgrims," a conceit that speaks to the quest-like narrative structure of this moral self that is always in the process of becoming. Notably, the self that is narratively constructed is not an individual achievement but a self constructed in a community. As Taylor puts it: "One cannot be a self on one's own." A self is always

¹³MacIntyre 193.

¹⁴MacIntyre 193.

^{15&}lt;sub>Taylor</sub> 34.

¹⁶Taylor 34.

¹⁷Taylor 47. Taylor builds from Heidegger's discussion of the temporal structure of being—especially Heidegger's essential argument that we know who we are as beings who become—to make a strong case for narrative identity that is, at base, a moral identity: "From my sense of where I am relative to 'the good,' and among different possibilities, I project the direction of my life in relation to it. My life always has this degree of narrative understanding, that I understand my present action in the form of an 'and then': there was A (what I am), and then I do B (what I project to become)."

constructed by reference to some defining communities. This dialogical self depends upon what Taylor calls "webs of interlocution." 18

Murdoch's discussion of moral choice that so challenges dominant conceptions of the will also depends upon an essentially narrative conception of the self, though she does not specifically speak of a "narrative self." She writes:

The place of choice is certainly a different one if we think in terms of a world which is *compulsively* present to the will [the existentialist position she opposes], and the discernment and exploration of which is a slow business. Moral change and moral achievement are slow; we are not free in the sense of being able suddenly to alter ourselves since we cannot suddenly alter what we can see and ergo what we desire and are compelled by. ¹⁹

In this African-American community, moral transformations of the will are often couched in a particular narrative genre, as *healing narratives*, where the self is a moral one in the process of becoming. Sonya portrays her most difficult struggle as battling her initial bitterness and anger. She describes her gradual ability to overcome these as "healing" from difficult emotions. Many personal stories are intertwined in this case. It is repeatedly underscored in our data that one of the most significant contexts Sonya draws upon to make decisions about how to care for Gus, or to envision what kinds of moral decisions she faces, is her own unfolding life. This is a life depicted in highly narrative terms, in terms of dramatic shifts, of befores and afters, especially those centered upon the accident itself. Gus's accident, she says, "altered my total sense of being."

She recalls how unfamiliar the world was in which she was suddenly plunged. When she was pregnant, she heard about the usual childhood diseases, but no one told her "how to deal with a child when he's severely burned." This new world has confronted her again and again, for

no matter how you think you've conquered it, in one way, you know it's always something new that comes up. When you think, "OK, I've got this down," you know, something new happens. Maybe there is a new surgery the physicians tell you about, and you have to face your fears all over again, or maybe he will be teased now that he's in school, and you'll have to deal with that.

These situations, which must be "dealt with," could be handled theoretically as moments of moral choice. But for Sonya, they are understandable as episodes in her unfolding life story and are most deeply intelligible from that narrative perspective.

This narrative perspective of a life also provides a way for her to situate the on-going work of making good choices about how to care for Gus to a broader re-making of her own life. She believes she has become a better person because this has happened to her. She was once rather "judgmental" of people, but the accident "made me a better person.... 'Cause I used to be like really judgmental. Like, 'Oh, what's their problem?' Or, you know, 'What's wrong with them?' But it kind of made me realize that, you know, people do the same thing that I did to others." She responds to this not only by trying to protect her son, but also through a moral reenvisioning that has allowed her to "embrace" the pain of others.

Conclusion

Hoping entails the ability to maintain what Hirokazu Miyazaki calls a "prospective perspective." It generates a narrative task. This narrative work involves more than telling stories

¹⁸Taylor 36.

¹⁹Murdoch 39.

about past events. It also involves the creation of stories about personal transformation required in order to continue to hope, and to revise one's hopes, no matter how desperate the circumstances or how bleak the prospects. Thus, these stories concern the future as much as the past, and the moral struggle entailed in finding a way to live with uncertainty.

Willing enters the picture in a central way because the struggle is so difficult. But the intimacy of connection between willing and hoping is most visible only if the will itself is reconceptualized. I have offered a narrative picture of moral willing that defines it as reenvisioning and re-orienting, emphasizing willing at particular choice points as inextricably bound to larger moral projects. Among the African-American families among whom my colleagues and I have been carrying out research, moments of willing, of having to choose, are experienced as parts of histories—battles fought; characters changing or failing to change; moral healing engendered not only through one's own efforts but offered, as gifts, through the actions and attitudes of significant others, both human and spiritual. Above all, this moral willing is connected to the project of coming to be a different, better kind of person, one who acquires the strength to face unexpected hardships and to treat the world more compassionately. This project is a long one, and its achievement is not guaranteed.

Biography

Cheryl Mattingly, a cultural and medical anthropologist, won the Victor Turner Prize in 2000 for her book *Healing Dramas and Clinical Plots: The Narrative Structures of Experience* (1998). Her essay entitled, "In Search of the Good: Narrative Reasoning in Clinical Practice," was awarded Best Essay for Medical Anthropology in 1999, receiving the Polgar Prize from the Society for Medical Anthropology. She is co-editor along with Linda Garrow of the well-received collection *Narrative and Cultural Contributions of Illness and Healing* (2000).