

Chapter 3

Resilience, Disparity, and Narrative Phenomenology: African American Families Raising Medically Vulnerable Children

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Introduction

In my home discipline of anthropology, studies of health among marginalized or oppressed peoples tend to emphasize the pernicious consequences of economic and political inequality. Anthropology has relied upon a host of powerful intellectual voices to give analytic depth to accounts of suffering and disparity. This important scholarly focus, while fruitful, has tended toward the unfortunate consequence of offering an overly one-sided picture of people's lives. People not only suffer, but they try to do things to ameliorate suffering and to create lives worth living. What about the aspirational aspects of life, what one might call moral striving? This chapter asks: What truths might we uncover when attending to not only suffering but also to people's attempts at realizing good lives even in unpromising circumstances? How might we look at the inventive qualities of moral striving? What kind of analytic frameworks might serve us in addressing these kinds of questions?

A focus on resilience, especially as a moral phenomenon, offers one starting place. As the title of this volume suggests, there is growing interest in resilience among medically vulnerable populations. Resilience focused studies often wed a health disparities concern with an effort to look at what allows marginalized people to thrive—or fare better than many—despite radically difficult health and social circumstances (Ager, 2013; Anderson-Fye, 2010; Panter-Brick, 2014; Panter-Brick & Leckman, 2013; Rutter, 2013; Wexler, Difludio, & Burke, 2009). Some of this work explores crucial and subtle interplays between resilience and vulnerability (e.g., Mullings & Wali, 2001). This represents a significant paradigm shift for many disciplines (not just anthropology) since most work on health disparities has focused on risk and negative outcomes rather than the complementary phenomenon of resilience (Panter-Brick, 2014). This

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paradigm shift can help correct for an overly narrow focus on risk, vulnerability, structural violence, and social suffering. It also—at least potentially—raises essential conceptual questions about agency and about how to investigate what morally matters to people’s lives. This is especially the case if “resilience” or “well-being” are not defined by predetermined functional outcomes (as they often are) and inquiry is opened up to investigation of how these, or other salient concepts, shape aspirations among the people one studies. As anthropologist Panter-Brick has contended, research on resilience must concern itself with “what really matters” (Kleinman, 2006) and this, in turn, takes us to “the moral dimensions of human experience where people live a life of great uncertainty and danger” (2014, p. 442). And as she further argues: “Agency in resilience does not mean extraordinary action; on the contrary, many scholars forcefully argue that resilience... is predicated on the competence and resourcefulness of everyday life” (2014, p. 441).

This chapter addresses resilience in this more open-ended sense. I explore how African Americans families raising children with significant disabilities and medical vulnerabilities attempt to create greater resilience in their families and communities despite barriers and vulnerabilities, and the dangers and hopes these efforts entail. As I will argue and try to show in what follows, my ethnographic material presses me to understand a term like “resilience” by connecting it to what matters in people’s lives, to their deepest moral concerns and how they understand what makes life worth living.

I offer the following example.

Experimental Soccer and the Good Life: Resilience, Suffering, and Moral Striving

It could be one of any thousands of soccer fields scattered throughout America: grade school children in their uniforms running up and down the grass shouting to one another as their parents cheer them on. It is an ordinary Saturday afternoon event repeated in countless towns and cities across the United States. Except that in the center of this field, as screaming children fly by, is a boy in a wheelchair being madly propelled by another boy as, together, they too head in the direction of the ball. His father and mother stand on the sidelines watching the action. The boy’s parents, Tanya and Frank, have three children—two girls and a son, Andy, who is their oldest. Andy was born with an extremely severe case of cerebral palsy that not only leaves him physically disabled but very cognitively impaired as well.

Tanya is one of those mothers determined to fight for her son’s rights to good schooling and she is fierce in her determination to stand up to school board members, principals, and other public officials in order to get good care for her son. “It’s my Jamaican blood,” she laughs, justifying her willingness to battle authorities.

But she credits her husband, Frank, for opening her eyes to her son’s capability to participate in everyday children’s activities that she would have shielded him from otherwise. Her husband is an athlete, a natural at many sports, and a son—his son—should love sports as much as he does, he maintains.

Frank decided that he should get Andy involved with the local children's soccer team. Tanya, however, was terrified and absolutely refused; they fought about this for several years. But finally, Frank prevailed and Tanya let her son go out onto the field. During one of the games, just as she feared, Andy's wheelchair was accidentally knocked over and he toppled to the ground. But, to her great surprise, he was not only unhurt but he didn't even act frightened. This is a story Tanya has told more than once. It moves her every time; catching her up short, not only the delight of it but also this realization that despite her determination that others view her son as capable, she herself underestimated him and the community surrounding him. This experience created new hopes for her child and it also challenged her own self-understanding as "good mother." She has asked herself, with some anguish: How did I not see what my child, and my community, could do?

I came to know Tanya and Frank as part of *Boundary Crossing*, a long-term ethnographic study among African American families in Los Angeles. The short story I have told reveals something about the ethically nuanced character of hope. The story is an opening vignette in a recent book (Mattingly, 2014) in which I explore the moral complexities surrounding parental care of medically vulnerable children. I have repeatedly been struck by how often parents respond to the suffering of their children by trying to transform not only themselves but also the social and material spaces in which they live. Parents like Tanya struggle to cultivate more morally worthy characteristics—to become better parents—in the face of immense demands illness and suffering can bring; to "step up to the plate," as one father put it, in order to care for their medically fragile children. These practices of care are undertaken in circumstances that are always fraught and sometimes seem impossible spaces in which any "best good" worth acting upon can be found. Parents may even carry out moral experiments, such as the reinvention of a local soccer game, as part of raising their children. These small experiments also invent, or reinvent, hope.

What does this say about resilience? Certainly the story of Tanya and Frank does not offer an obvious example of a resilient family in any straightforward sense. We see the earnest struggle of these parents to create a good life for their child and their family, a life that they can endorse morally and that they find personally and socially significant. Their attempts and experiments raise hopes but are (at least for Tanya) also accompanied by new vulnerabilities. Examples like this suggest a picture of well-being or resilience less as a stable achievement or state of being—something one has or lacks—so much as an ongoing practice. This is a practice where the very criteria defining well-being can have very family-specific meanings, may not be shared among all family members, and may shift over time. I am speaking of a complex and fraught practice, yielding gifts of trouble as well as joy and satisfaction.

A Narrative Phenomenology of Resilience

In this chapter, my conceptual and empirical starting point for a consideration of resilience is a narrative one, a narrative phenomenology which is grounded in the lives of particular persons and intimate moments of family and clinical life. In previous work,

I have not used the vocabulary of resilience or well-being. I have tended to associate such struggles and aspirations with quests for “hope,” a term that does not cover exactly the same ground as “resilience,” but bears a family resemblance. The families I have studied do not use words like “resilient” to describe themselves, but they do speak of hope, and just as often, of bitterness, anger, and despair.

What might a narrative approach offer to an investigation of resilience? Even beginning to answer this requires immediate clarification because I am not simply referring to storytelling. Ordinarily, when we speak of narrative we have in mind either a kind of artifact, a text, or a performative genre, a particular kind of speech act. For my purposes however, this framework is not large enough to encompass a narrative portrait of resilience. Storytelling and the reception of cultural texts represent one small part of what I mean by narrative. Narrative phenomenology, as have my colleagues and I have construed it, builds from a dramatic perspective on social action that has a significant, if minor, history in social thought. More than 70 years ago, Kenneth Burke (1945) proposed “dramatism” for the study of communicative acts. He sought to offer a framework for understanding human action which would distinguish it from the leading theories of his time that were based on behaviorist models of action. Behaviorism, he declared, was “designed to study people as mere things,” (1966, p. 53) as he put it, needing no strong theory of agency and intention—of the centrality of *motive* to practical life and practical understanding. In anthropology and sociology there are multiple strains of dramatism which include such key figures as Victor Turner and, very differently, Erving Goffman. Performative and phenomenological approaches to social action and experience, especially studies of ritual as social drama, have also played a contributing role (e.g., Csordas, 1996; Kapferer, 1983; Schieffelin, 1996).

I have relied upon a dramatic image of action to argue that practical action involves both the ongoing apprehension and the co-creation of acted stories, including (at times) dramatic moments that engender significant experiences. Practical action, from this view, is highly eventful and the eventful features of everyday life are worth particular attention. The anthropologist Michael Jackson’s (2005) description of an “ethnography of events” is close to what I have in mind. An ethnography of events he tells us “seeks to explore the interplay of the singular and shared, the private and the public.” Everyday life presents actors with “a series of situations whose challenges and implications always ramify beyond the socio-cultural....” Thus, attention to events “illuminates what is at stake for those involved,” as well as carrying “ethical and practical implications that far outrun specific individual intentions and awareness” (Jackson, 2005, p. 75).

This narrative phenomenological approach speaks to actors’ attempts to discern (or, perhaps more accurately, to dream) hopeful future stories, and the vulnerable, or even tragic possibilities inherent in this project. It presumes that cultural meaning is emergent and unstable (even a matter of cultural border crossings as actors navigate their way in multiple cultural worlds), and that it is produced in specific historical contexts by particular actors who are in the business of trying to live their lives.

In narrative terms, actors are trying to discern what story or stories they find themselves a part of, which ones they ought to be trying to further and which they ought to avoid, and what their narrative possibilities are as these change over time (Mattingly, 2010).

I call upon phenomenology to enrich this narrative approach because of phenomenology's investigation of lived experience, especially the experience of human time. From a phenomenological perspective, time is not the next mechanical progression of clock time. Rather human time or lived time is experienced as a "threefold present"—that is, what we call "the present" or the "now" is configured in a temporal structure. This configuring structure includes both past and future because both memory and anticipation are brought to bear in our experience of a particular present moment (Ricoeur 1984). Phenomenologists often use the example of how we hear the note of a song—a present moment of sound. That note is not heard alone, as a singular sound, but is heard by us as something configured by the notes that have preceded it and those we anticipate (through prefiguration) that will follow it. Put in more cultural language, our memory (of the sounds we have heard) and our anticipation (of future sounds) have been shaped not only by the immediate past (the song's earlier notes) or anticipatory future notes that we expect to hear—these expectations of past and future are culturally shaped. We are familiar with a repertoire of types of songs and this cultural repertoire will shape memory and anticipation.

If we take the example of the soccer game, we can see it in narrative phenomenological terms by noting that the "now" of a particular soccer game, say the one in which her son is pushed over and does not mind after all, presents itself an experience to Tanya in light of a past (which includes the many years of arguing with her husband) and an anticipatory moment—in this case, the surprise of an experience in which her anticipatory understanding of how things would unfold (her son would be hurt, this would be a disaster) is met with an event she does not anticipate. Her son's response challenges her own expectation of his vulnerability. This is not a passive challenge. Rather, this experience affects her so profoundly that it actively shapes how she begins to see her son's future and her own. I have offered an oversimple analysis of the phenomenological depth of her experience, but I hope to have at least intimated what a narrative phenomenology of experience might bring to studies of people's aspirations for good lives and for well-being as an unfolding, effortful practice.

Resilience and Health Disparities: A Narrative Phenomenological Approach

As I discussed earlier, resilience has become an important concept in health disparities research because it can supplement an overly narrow focus on obstacles, barriers, risks, and social inequalities. It does so not by presuming that these are insignificant but rather by offering complementary attention on the circumstances

and activities that permit people to thrive, despite formidable barriers. Using a narrative phenomenological approach, I offer the following example of a low-income African American mother (Andrena) who has a daughter with a severe form of brain cancer. Her situation illustrates a common issue in health disparities—access to care. Andrena’s daughter had a long delay in diagnosis and the cancer had progressed far before she received any treatment.

Just as with Tanya and her family, my example of Andrena and her daughter will not offer us a straightforward picture of thriving. Rather it reveals the many efforts that Andrena makes to promote thriving—or, more accurately, living the best possible life—despite the desperate situation she and her daughter face. The situation I describe below takes us into a clinical space. It suggests how a clinical encounter can contribute significantly in helping families and patients realize good lives even when a cure is unlikely or medically impossible. And it also suggests that this clinical contribution can come in the form of small dramas rather than large medical interventions. Such small dramas go virtually unnoticed and certainly undocumented within the clinical world. And yet, they may be of profound significance to families and patients.

The Witches’ Tea Party

For nearly a year, Andrena took Belinda to emergency rooms all over the city, seeking some kind of diagnosis for her increasingly ill child. Time and time again, she was told to go home, that nothing was really wrong. Finally, after Andrena’s very strong protests that she would not go home until someone looked at her daughter because she knew something was very wrong, a doctor examined her and recognized that there was a serious problem. Within 2 days, Belinda was diagnosed with a brain tumor that had grown unchecked for a year and was, by the time of diagnosis, the “size of an egg.” Prognosis was not good; no more than 60% chance of recovery, the doctors told Andrena. Belinda had surgery and radiation, followed by chemotherapy.

After surgery, Andrena and her Belinda spend at least 2 days a week at the hospital for the next year and a half. Tuesdays are chemo. Thursdays are outpatient physical and occupational therapy. Her oncologist is someone Andrena gradually comes to trust, and there is a physical therapist who Belinda is particularly fond of. Andrena credits this physical therapist with teaching Belinda to walk again after surgery, a healing drama of momentous proportions when one hopes for a child to recover. And Belinda loves her therapy days because (a) she does not get a shot and (b) she gets a chance to play with some new people who, sometimes at least, know how to have fun. I describe a moment when a narrative is created in a treatment session with one of her occupational therapists—a narrative which is both hopeful, and, in a sense “ready to break.”

An occupational therapist, Amy, who was not so familiar with Belinda had just taken over the case. She tried for a few sessions, very unsuccessfully, to get Belinda

involved in some fine motor activities, like cutting and pasting pictures from magazines onto a page in some collage art activity. Belinda was generally bored and fretful, repeatedly jumping up from the table to wander off and see what other toys might be around. About the third frustrating session, Amy had an idea. She noticed that Belinda gravitated to some of the play clothes kept in the cupboards of the little treatment room where they had had their sessions. Also, Belinda was obsessed with the sink in the treatment room, each session heading immediately to it to wash her hands and then proceeding to take the sponge and wipe down the counters. Amy decided they should have a tea party, in fact a witches tea party. Belinda was delighted. They tried on many clothes together, Belinda attempting to tie various scarves on her bald head, preening in front of the mirror, and then settling with great delight on wearing a gigantic black witch's hat. The therapist, Amy, similarly donned a hat and Belinda even found one for me to wear, though I was trying to sit quietly in the corner and take notes. They set the table, placing their dishes just so, invited a few stuffed bears and other creatures to the tea, filled the teapot with water (Belinda's favorite part) and had some lovely plastic bagels to go with their drinks, which they sipped decorously in a ladylike way. There were, of course, many fine motor components to the party (scarve tying, buttons buttoned), which was a great hit.

How to Throw a Witch's Tea Party: The Narrative Emplotment of a Therapy Session

The interlude just recounted marks a shift from a therapy time the therapist designates as "scattered" to a focused and dramatic moment, narrative time governed by a desire, suspense, drama and a sense of the whole. Play clothes and plastic bagels transform the pair into festive witches eating and drinking with friends. Few words are spoken but this is a story all the same, and one imbued with symbolic density, a story that signifies. The depth of its signifying power is never guessed at by the therapist who so beautifully orchestrates it. Understanding why this therapeutic moment holds power for Belinda and her mother depends upon knowing more about Belinda's life than this therapist does. However, the therapist is fully aware that she and Belinda have effected a transformation in this part of the session. They have managed to shift from clinical time which is scattered, where she cannot get minimal cooperation from Belinda, and where, if she is unlucky and this persists, she may have to force Belinda to perform a set of tasks directed to discrete problems (weakness of her left side and especially her left hand, attention deficits caused either by the original tumor or brain damage from the surgery). She knows that out of an inauspicious beginning, they move into imaginative play where treatment of pathology is embedded within such merry adventures as dressing up as witches and pouring water from a teapot.

The drama relies upon their ability to move into a cultural script they share, one surrounding the everyday business of making tea and throwing parties. They make tea, they prepare snacks, they share food and drink with others. For this purpose, water becomes tea, stuffed creatures become honored party guests, and plastic bagels the tasty snacks fit for a proper witch's tea. The therapist's ability to follow the "pacing" of Belinda and to build opportunistically on what intrigues her, allow all of us—as actors or audience—to enter the "same story"—to create a healing story—for the space of a therapy session. But it is only when placed in context of Belinda's (and Andrena's) unfolding life that the real drama is revealed. This session connects Belinda to everyday life in the sense that it plays out a familiar canonical scene. (Belinda, like other children her age, loves nothing more than playing at being grown-up and cooking is a quintessential everyday activity reserved for those older than herself.) But its dramatic potency is due to the way it disconnects; it creates a breach from the life Belinda has been living since her illness. Amy and Belinda make an upside down story of her life—one which connects to Belinda's life but is powerful for Belinda because there are so many reversals of everyday life.

This little performed narrative connects clinic life to a hopeful plot Andrena is fiercely trying to live out, despite the devastating losses that have recently occurred. This story is one where Belinda has a joyful childhood, where she lives to the fullest. This hopeful plot requires such nurturing because it runs counter to the life story that has been unfolding. It is an upside down story in light of the many losses of her recent life. Here is a brief catalogue of the most important ones: (1) she leaves preschool, which she loves, and stays home all the time, away from her friends; (2) her father moves out and her parents are now divorcing; (3) she and her mother move from a small rental house to an apartment because her mother has been fired (missing too many days due to Belinda's illness) and can no longer pay the rent on the house; (4) since they are now cramped for space, her 23-year-old sister, who had been living at home, moves out, taking her son who is Belinda's age and is very close to Belinda; (5) Belinda loses her old neighborhood and now lives in a place with no yard; (6) Belinda's grandmother is diagnosed with stomach cancer and has become quite ill. She cannot visit Belinda as much as she once did; (7) Belinda eats so little, has grown so thin from the illness and the chemotherapy, that her mother now gives her a baby bottle because she will eat more that way. Belinda seems to be hurtling backward in developmental time.

Belinda cries sometimes at the loss of school playmates, father, and nephew, and is frequently mutinous at her mother's constant entreaties that she eat. Eating has become something of a battle between the two of them, and food has become a source of worry rather than fun. And in the midst of what has felt like a losing battle to get Belinda to eat, to keep enough food in her, and keep her from losing more weight, this therapy session has offered her a chance to feed others. As a witch at a tea party, she is the nurturer of other creatures as well as herself. She prepares the food and sets the table and brings everyone together. And she does so in disguise. She is Belinda but not Belinda, for she has donned a mask, a new costume, a new identity—Belinda the friendly witch. And she is not at a tea party by herself—what kind of party would that be—but with another witch, the friendly therapist who has

finally thought up something fun to do. Even the outside anthropologist is invited to join, as Belinda insists that she wear a witch's hat too. So Belinda, who loves people but has been spending more and more time alone, can also orchestrate this social gathering, this social drama—thanks to the clever organization by Amy, the therapist.

Amy embeds certain activities directed to discrete disabilities (an impaired left side) within an activity which she knows the child finds absorbing. The most intense moments are dramatic in their quietude. Time slows. Within this pause, it is possible to glimpse a different child. This glimpse is intensely in the present, which takes on its own authority. But the very intensity of the present facilitates a foreshadowing gaze. This is not a predictive gaze so much as a freewheeling speculation; Belinda is transformed into a cheerful witch capable of caretaking. These are not realistic images. But their very fancifulness lends them power and intensity—even a certain seductive authority. Perhaps Belinda *will* emerge from a scary, isolated world where she is not only weighted down with a life-threatening illness, but faces the losses of friends and loved ones as well. And, perhaps the point is not only about some unlikely future but also about the possibilities within a present moment, a moment where Belinda does emerge as the lively, mischievous girl that her mother fondly remembers her to be, before she was struck with this illness.

Frail Dramas: The Invisibility of Healing Moments

Although the therapists may not realize this, their work has helped Andrena to envision a “return to life” after surgery, in which Belinda is able to laugh, walk, and play. In fact, Andrena sees these therapeutic interventions as so pivotal to Belinda's well-being that, unbeknownst to the therapists, she has built an entire home version of the rehab gym.

In this example, the therapist is well attuned to Belinda, but she is not at all aware of how her work fits into the larger life world of this child. She, and the other therapists who work with Belinda, is fully unaware of the extent to which Belinda's mother has incorporated the work of the therapists into her home life. The four therapists I interviewed about Andrena strongly concurred (in separate interviews) on several points: (a) Andrena “loved her child to death”; (b) She “popped in and out of sessions” which several therapists found troublesome since all struggled hard to hold Belinda's attention and Belinda frequently looked for her mother. Often she didn't come to the session at all but disappeared, which also disconcerted or annoyed the therapists; (c) Andrena seemed “pretty overwhelmed,” a phrase repeated by all the therapists. As one put it, “I just think there's lot more going on in her life. She's just got such a full plate. I just get the impression that she's really overwhelmed”; (d) Noting Andrena's devastation at her child's illness and her life, which has become overwhelming, these therapists often mentioned that Andrena did not appear to be “absorbing” much of what the therapists were telling her. She often seemed rather “dazed” or “spacey” they said.

These remarks were made in sympathetic tones, a sympathy quite lacking when therapists describe parents *not* perceived as “loving their children to death.” However, Andrena commits a breach from what, in the context of clinic culture, is approved parent behavior. She neither sits through the entire session nor waits patiently in the waiting room to be called upon by therapists as needed. Instead, she “pops in and out” and “disappears” for stretches at a time. Therapists have few means for evaluating whether parents are good “partners” or not; being available for therapists is an important (and generally unspoken) rule. The “good parent” shows up on time and cooperates with the therapist, assisting, watching from the sidelines or waiting in another room, as the therapist deems most appropriate. Andrena’s violation of this cultural code requires a narrative explanation. The therapists’ story about her life that explains this violation (she “needs a break,” she is “overwhelmed,” she “has a full plate”) is quite correct, as far as it goes. They have read with unerring acuity Andrena’s love for her child and guessed with equal accuracy that there are many more difficulties Andrena faces.

What they have missed, in their sympathetic reading, is Andrena’s capacity to be overwhelmed, to violate the cultural code of the outpatient rehabilitation unit, and still be able to “read” their minds, to see what they are doing and why it is important for her child. They are utterly unaware of the extent to which Andrena has gone beyond anything they would dream of asking in incorporating therapy life into home life. Andrena views all the rehabilitation therapies as utterly central to her quest to, in effect, bring Belinda back to life after her surgery. When I have asked Andrena what she thinks the point of therapy is, she always returns to a moment after Belinda’s initial surgery, painting a vivid picture of how therapy, as well as her family, has helped to bring Belinda back to life. Therapy’s role is to get Belinda “back to where she was before she got bad.” Because, she explains, “after the surgery was over, she could not even walk. She could not use her hands, well at least her left hand. She could not use her left eye. So she couldn’t do anything...when she, you know, was out of surgery and they moved her downstairs, it was like she couldn’t do nothing but just lay there. She wouldn’t even laugh until my grandson and my father came up here to the hospital. And then, she like, my grandson was making her laugh and she was like starting laughing. She got all in good spirits... She just started laughing and she was coming, like coming back to life.”

In Andrena’s narrative of Belinda’s “return to life” after surgery, the therapists are instrumental, even helping her to walk again, one of those recovery moments that are always dramatic for parents. At one point, in remarkable synchrony with many of the therapists’ accounts of how they work with children, Andrena relies on musical metaphor to depict the skill of the therapists. Jane (Belinda’s favorite physical therapist) was so good with Belinda because she tried to “fall into Belinda’s mode of behavior.” The therapists were good because they knew how to “slow down” and “take time” with Belinda. They push Belinda because they are able to figure her out.

What would most astonish the therapists is not only Andrena’s accuracy at reading what they have been doing, and why it matters, but also how thoroughly she has built upon their work. She is, in fact, the dream parent, the one that therapists long

for. She has transformed her entire living room in her small one bedroom apartment. It looks like a compressed version of the large rehabilitation room in the outpatient clinic. There is a child-sized basketball hoop, a slide, tunnels to crawl through, even a cheaper version of a “ball bath,” a standard piece of pediatric rehabilitation equipment. Andrena remarked, who saw nothing extraordinary in what she’d done, explained matter of factly that she thought it would be good for Belinda to have this setup at home so that Belinda could work more on the therapeutic activities Andrena had seen the therapists do with her at the hospital. She laughingly noted that Belinda’s cousins and nephew were her “home therapists” because they got her to play on all the equipment.

It is not just Andrena who tries to create experiences in which the hopeful stories born in therapy are lived out. Belinda too looks for such opportunities. And when the occupational therapist has the good sense to offer the chance for a witch’s tea party, Belinda takes full advantage, laughing as she admires herself in her extravagant witch’s hat. This is a particular way to consider “learning by doing” or “learning from experience,” where the task to be learned is an emotion, if you want to put it that way, a whole perspective on life.

Life is complex and it would be foolish to presume these few months of occupational therapy sessions with Amy as single-handedly altering Belinda’s fortunes. But at the very least, it is clear that Amy helps Belinda and her mother to realize an image which is mostly hidden by her poor physical health, her grim prognosis, and her difficult home situation. One plausible story to tell about Belinda and Amy is that Amy played a vital role in cultivating hopeful possibilities for Belinda and her family. She saw something in this child at a time when the predictions of other health care professionals were grim. Better and more important, she could use what she saw or guessed about Belinda to help create dramas in which this picture was embodied, was made evident to everyone: mother, researcher, Belinda herself.

And yet, for all of the brilliance of Amy’s work with this child, there is a fragility that surrounds her interventions. While she recognizes her success in building fine motor skills, she fails to recognize the significance of these interventions in recrafting a tragic vision of Belinda’s future into the hopeful possibility of a “return to life.” One moral here, for health professionals, is that even when it is not clear what significance a session has, even when the parent doesn’t seem to be around, it is possible, very possible, that more is going on than even meets the clinician’s eye. It is possible that clinicians, more often and more powerfully than they even realize, may be contributing to the creation of life stories, offering hopeful moments with deep phenomenological impact.

Conclusion

In my narrative phenomenological approach, I have not presumed that resilience is something one can simply find but rather is a phenomenon embedded in the complexities and shifting character of people’s lives and social circumstances. I have

foregrounded the temporal complexity, historical situatedness and singularity of action, its ethical nature, its vulnerability in the face of an unknown future, and its imaginative character especially as revealed in the shadowy presence of futures not yet revealed.

I have also argued for the social qualities of resilience, its reliance upon communities that cannot always be predicted ahead of time but may be particular to a person's or family's situation (for example, a local soccer team, a rehabilitation therapy unit). In fact, part of the effort that parents make in trying to thrive includes searching for communities and social resources that can support their child's well-being. Furthermore, these social resources aren't simply found—they are, in part, created by the actors themselves. A soccer team becomes a different sort of team when it includes a child in a wheelchair—this social world is, in part, created by the actors involved. So, too, the rehabilitation therapists like Amy, and children like Belinda, who find their way into the kind of tea party that Belinda can especially enjoy.

Finally, I have noted the fragility of resilience-producing moments, the ways that they can be shattered because the actors who are so crucial to helping to create them are unaware of their own efforts. This bears particular significance when looking at the role of health care providers. In other work which goes beyond the purview of this chapter, I analyze some of the institutional features of health care provision that so often lead to this very unfortunate consequence (Mattingly, 2010; Mattingly & Lawlor, 2001; Mattingly 2000, 2007, 2008a, 2008b). In this chapter, I merely note this to underscore the ongoing and vulnerable work involved in creating something we might want to call “thriving” or “resilience” or “well-being.”

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