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Mothers as Storytellers

LINNÉA E. FRANITS

Motherhood and disability have always been inextricably intertwined for me, as I was born into a family where disability was already present in my sister's and therefore my parents' lives. You might say that I was born "wise," to use Erving Goffman's descriptor of people who are privileged by being closely associated with individuals who are discredited or stigmatized by a characteristic such as disability ([1963] 1986, 28). Disability is also part of my current daily experience, as I am the mother of a pre-adolescent boy who has a couple of diagnoses that "qualify" him as disabled. In this chapter, I explore how mothers construct narratives of disability and how disability can construct narratives of motherhood within relationships, be they maternal or not.

I tell some stories myself, but as an autoethnographer I also reveal my position within these stories, reflecting on how life writing is mediated by the expectations of culture as well as narrative scripts. By focusing on storytelling rather than the stories themselves, I hope to formulate a broader understanding of how narratives of disability and motherhood can construct each other.

THE POWER OF STORYTELLING

The word "storytelling," particularly when paired with motherhood, conjures up the iconic scene of bedtime-story sweetness where a small child is snuggled in the crook of a mother's arm while she rocks and speaks in soothing melody, perhaps reading from a book or simply relaying her

own version of a story while gazing lovingly at her little one. These can be emotionally laden moments. On the other hand, adults rarely read aloud to each other in this culture, and if not a designated performance, their storytelling is generally a more unstructured activity that happens around a dinner table or other social gathering. These stories can be emotionally ripe as well, of course, and although they often develop spontaneously, these narratives can also become scripts we recite as the situation dictates. In their research on the relationship between narrative and identity, Debra Skinner and her co-authors remind us, “These constructions of meaning do not happen in a vacuum. People learn to tell stories a certain way, to come to particular points of view, through participating in a community of tellers and listeners” (Skinner et al. 1999, 489).

And so, when I was asked to write a short memoir for a graduate class I was taking, it was easy to decide which story I should tell. I chose the story of the medical crisis my son had on his first day of life; it has all of the elements of a “good” story framed so as to follow a satisfying, typical narrative arc. I have told this story countless times and in fact regularly share it with classes of students in the health professions who are learning about the same cardiac defect my son was born with. There is even a slick PowerPoint version with dramatic photographs of my little boy with a long incision on his infant chest. However, for my class, I was instructed to write this autobiographical piece and then read it aloud to my classmates, which was not the typical way that I tell the story. I was confident at first that this well-practiced essay would roll off my tongue and that I would be able to time my words just so in order to give the audience an opportunity to respond as expected, always surprised and often moved to tears. I have found during my multiple retellings of this story that my listeners are often primed to hear my story in a certain way, and their expectations and response have in turn shaped the way I tell the story. I have tended to build this narrative with a typical arc of rising action, and the audience climbs that pinnacle with me. Just as a ride on a roller coaster has an expected incline, and the surprise comes when that incline suddenly turns at the climactic peak and quickly descends, the peak or climax in this story I tell is known to me but not to my audience, and so while I have come to expect their surprise, I do not feel my stomach flip. I pause; they tear up.

This telling became completely different. I found myself becoming more and more moved by the words I was reading, to the point where my eyes welled up with tears, which eventually spilled out onto my face as I was overcome with sobs. I was a mess. My kind peers passed tissues my way, and the professor was gracious and gentle as I tried to regain my composure. I was perplexed by my response and struggled to figure out why this telling of the story was such a different experience for me than my typical presentations. For some reason, reading my written word aloud multiplied the emotional impact it had on me. The story was the same as it always had been, and I already knew the admittedly constructed happy ending. The words on the page were somehow more real, more powerful because of their written and then aural form. As I heard myself reading these words to my classmates I became a listener as well as narrator, a participant who received the story and who was not in control of the happy ending. The roller-coaster track had become unfamiliar to me, and the turn startled me as it did the rest of the group. I was reminded that the story of my son's birth and early life was not the one I had mentally written before it happened, the one that other mothers had told me to expect.

EXPECTANCY AND EXPECTATIONS

Although the genre of disability memoir has truly established itself (particularly over the last couple of years), narratives about bodies tend toward stories about people with extraordinary athletic skill or beauty, or in the case of disability memoir, the overcoming of a disability rather than people with bodily difference that require medical intervention or that require accommodation. However, narratives of pregnancy and childbirth can cross between these categories and are some of the most often told stories of corporeal life. In the same way that a woman's pregnant contour invites the touch of near strangers, the mention of a woman's pregnancy seems to incite the storyteller in many women, who purport empathy but may simply wish to tell their own amazing stories. And these stories are indeed amazing because the pregnancy/childbirth process is so. Women (and sometimes men) are free to describe the most intimate details of bodily functions without fear of being stigmatized for it

because the narrative is well scripted and meets our preconceptions of what a story is expected to be.

My mother used to tell my own birth story to me in what became a tradition on each birthday. Because of her generation and old-world beginnings, she tended toward euphemisms in a kind of poetic way, saying “womb” instead of uterus and “labor pains” instead of contractions. Women in my age group who have grown up reading *Our Bodies, Ourselves* (Boston Women’s Health Course Collective [1973] 1992) are often more comfortable with the biology of childbearing and can be even more descriptive when telling pregnancy and birth stories. Maternity allows gatherings of women to discuss episiotomies and vaginal topography or troublesome incontinence, topics not typically part of polite conversation in our ordinary social contexts. These grounded moments are not stigmatized because they are a part of the expected narrative surrounding childbirth in this culture.

But what of the narratives that do not fit these expectations? When a child is born and disability or illness is present, the story changes. The climax of the birth can be superseded by the “tragedy” of a diagnosis. This kind of a story is less often welcomed by those awaiting the expected resolution of “normal” childbirth and may not even be shared in the same way. When disability or illness is present, the new mother may be stripped of her “expert” status regarding her child as medical personnel busy themselves with often critical tasks. Health care practitioners take over in constructing the infant child’s story. Some mothers and fathers share horrifying tales of physicians who recommended institutionalization of newborns diagnosed with disability. These stories and others like it are increasingly becoming part of disability narratives, as people with disabilities become more free or able to tell their own stories and to share the disheartening choices parents were asked to make. Most of the narratives about this kind of a choice are now being told by individuals who were not institutionalized and whose parents fought the recommendation to do so.

When a narrative about a birth does not traverse the expected arc (anticipation of the birth, to the climax of the birth itself, to the resolution of a healthy baby), there are alternative narrative scripts that mothers may choose that fall into what G. Thomas Couser (2008, 190) describes

as formulaic “rhetorical schemes” in his discussion of narratives of disability. One of the most familiar narrative patterns is one where the individual with the disability is either cured or gets beyond his/her condition in some other way. This story always has a happy ending and is often strongly reinforced by those who receive it. The narrative of overcoming disability can be seen in mothers’ stories of the resolution of “normal” life after the initial disappointment about a child’s diagnosis and the salvation offered by professionals. Truthfully, this is how I have constructed my own story about my son’s diagnosis shortly after birth; I tell the tale of his ability to overcome a severe cardiac defect and the intervention offered by medical experts. I do not mean to suggest that this story is inaccurate or that his life wasn’t saved by medical expertise. Rather, I am compelled to tell the story this way because both the expectations of my listeners and expectations I have internalized are very powerful. There is more to the story than the details I typically include, but those that don’t fit the prescribed shape I leave unsaid.

Sometimes, a mother feels the need to construct a narrative of disability that fits the listeners’ expectations. This “wish fulfillment,” as Simi Linton describes it, is fueled by the desires of people outside of the disability experience as well as people living disability narratives who have internalized those tropes and become characters in their own stories, rather than more authentic autobiographers (Linton 2008, 177). When my son was discharged from the hospital after his third surgery in a two-year span, I was asked by a friend of the hospital chaplain to submit an essay for a book of inspirational stories he was collecting to distribute to other families who were going through similar medical experiences. At first I was excited to have an opportunity to tell my son’s story (or perhaps my own story), but I quickly recognized the impossibility of the task as set out. Although I can be spiritually reflective about my motherhood and my son’s diagnoses, I really don’t want to construct the story to insure that it inspires readers.

DISABILITY, THE SEQUEL

Some find it ironic that having grown up with a sibling with disability and spending much of my childhood longing for a more “typical” family,

I have a disabled son myself. Others frame it as a cruel injustice, and still others see it as fulfillment of a divine plan because I have been “prepared” to be a mother to someone with disability. None of these formulations really fit the stories I construct about my life experiences, although I have tried each on for size at times. More frequently, I examine my mother’s position, culturally, historically and geographically, and how that may have dictated her actions and compare it to where I perceive myself to be. Some similarities between our situations are striking, but our stories are not and could not be the same.

My mother and I have each experienced the pain of watching a child undergo major surgery on multiple occasions, when medical fragility required that precious moments be spent in the antichildhood context of the hospital. We have each spent countless hours in waiting rooms anxious to hear the surgeon’s assessment of an outcome of a procedure. We have felt the support of friends and family that go along with these medical crises and know that these are the dramatic stories that people want to hear. As a child, I sought the attention that my sister received during these periods of intensity and eventually learned that I could get some of that attention by telling her story. As a mother, I also learned to manipulate the story of my son’s critical moments, sometimes for attention, sometimes for educational purposes, and sometimes just to tell a good story.

But in addition to my sister’s acute neurological episodes and my son’s critical cardiac status, each has what is characterized as a “developmental disability” that, because chronic, doesn’t generate the same interest among the audience as a life-or-death operating room tale. In my sister’s case, “mild mental retardation,” and for my son, “high-functioning autism,” these experiences are perceived as nonnormative states that are perhaps pitied but do not generate narratives that are as interesting to the public as dramatic hospital stories. I have presented the story of my son’s cardiac condition to a number of college classes as well as academic conferences but have never been invited to speak about his autism. I conjecture that the narratives associated with a disability that will not be cured, or overcome, do not fit any template of popular disability narrative in our culture, and so these stories are not sought out. The daily care-giving associated with my sister’s short-term memory difficulties or my son’s anxieties about fire

drill alarms doesn't provide as compelling a story for most, and so these narratives go untold.

MY MOTHER, NOT MYSELF

I couldn't begin to tease out where my experiences watching my mother construct disability narratives about my sister inform my own maternal authorship about my son's disabilities, yet I am confident that they are interwoven. Sometimes women say that they understand their own mothers better once they become mothers themselves, and one might think that especially true of mothers of children with disabilities. But disability complicates motherhood in very individualized ways. Eva Feder Kittay is perplexed by her own mother's unfathomable advice to institutionalize Kittay's daughter Sesha when her numerous disabilities were initially recognized. Kittay's emotional pain is palpable when she asks "My model of maternal love asking me to discard my child? . . . I couldn't comprehend it" (1999, 152). The only way that she could frame such a foreign sentiment was by delving a bit into her own mother's history with disability, which most likely included horror stories from the Holocaust, where revealed disability meant certain death in a concentration camp. Kittay understands that her mother wishes to protect her granddaughter with "preservative love" by hiding her away (163) but simultaneously maintains her own perspective to create a "protective circle" of support around her daughter rather than institutionalize her (Goffman [1963] 1986, 97).

As I have already mentioned, my mother's choice of words about childbirth clearly identified her as a product of her generation and place. Her vocabulary about disability was equally culturally positioned, and she unwittingly taught me the power of negative language about disability and how certain words could stigmatize. One particular story was logged in my brain when I was a six-year-old girl, sitting on the beach with my nine-year-old sister and my mother. A wind picked up and lofted our little clamp-on umbrella right off the webbed chair and into the sea; my mother did her best to jog after it as it somersaulted across the sand, rolling yellow with white polka dots, but she was unable to reach it. When the surf grabbed it and it began to move further towards the horizon, my

sister burst into tears for fear of losing our stuff. She pointed and cried, repeating, “The umbrella! Get the umbrella!” That’s when my mother shouted back at her with a short-tempered, almost mean, “Stop crying!” I was surprised by her sharp tone, which she rarely used and particularly not to my sister. But then I was even more surprised by her next statement, “People will think you’re retarded or something!” I was shocked and perplexed and for the first time really wondered how my mother viewed my sister. Wasn’t she “slightly” retarded? Isn’t that how some people had described her? What was my sister anyway if not “retarded”? What word would she use? Then I recognized why my mother used that tone with my sister—she was embarrassed. She didn’t want people around us to think of my sister as being cognitively disabled and particularly not that dreaded word—retarded. My mother was never ashamed to tell the story of my sister’s neurological trauma and almost bragged about how well she recovered from brain surgery each time. Yet the narrative that accompanied the word “retarded” was not a story line my mother embraced. Even as I write this, forty years after this event, the word retarded is in the news as an ableist epithet being used in a major motion picture. Simi Linton includes the word “retard” in her list of “nasty words” in her discussion of how language related to disability should be reassigned new meaning, as defined by those living the narratives of disability (Linton 2008, 176).

My own choices to use the words autism or autism spectrum disorder when describing my son also depend on my audience, but I find them less stigmatizing than my mother did with the word retarded. I likely use these terms as shorthand, tapping into the public awareness about autism and the preconceived notions people have about what individuals with autism are like. Although there are plenty of misconceptions, I can explain some of my son’s unusual behaviors with the simple phrase “he is on the autistic spectrum” worked somewhere into the conversation. Although I theoretically resist labeling people with diagnoses, in practicality I make use of labels to my son’s advantage, such as in school to get the supports that help him to benefit from the instruction. Perhaps because autism is sometimes associated with purported savantism, or extraordinary talent, it is not as stigmatizing a word to use as words associated with subpar cognitive capabilities. It is not uncommon for people to

ask me, once I've outed my son, what his extraordinary talent is. Admittedly, I use this opportunity to brag in a way mothers of typical children might brag about their kids' accomplishments, but I eventually wind up concluding that my son's skills in whichever area I'm discussing are really just a little bit above average. My listeners may desire a more dramatic climax to the story to somehow balance the perceived tragedy of the diagnosis of autism, but I take pleasure in the "normalcy" of the ordinary.

DEPENDENCE AND CAREGIVING:

HOW DISABILITY NARRATES MOTHERHOOD

Mothers construct narratives of disability for a variety of reasons and in a variety of ways, yet the disability experience can write stories of motherhood, too. The most obvious understanding of this is the way that disability in a person's life can shape or construct her motherhood. Caregiving for children with disabilities often extends beyond typical timelines, and the "dependency work" associated with motherhood can be a lifelong commitment when disability is present (Kittay 1999, 156). These characteristics enabled my mother to avoid the "empty-nest syndrome," as—in my sister—she had someone at home who depended on her in a childlike way for forty years. My mother's identity was indeed formed by my sister's needs, which in turn became my mother's need to be needed. In my case, my son is my only child, and so my entire experience of biological motherhood has been informed by the presence of disability as it has been defined in his life. It is not that I wouldn't have a story if my sister and son didn't have disability, but I wouldn't have this story.

Disability can also construct narratives of motherhood for anyone considered to be a caregiver. Although disability is often equated with dependency, this is not the most accurate description of the dynamic between the individual with disability and the caregiver. Just as motherhood can be constructed to include "othermothers," caregiving can be seen as an interdependent exchange between an individual with a disability and caregiver(s), including mothers. Eva Feder Kittay recognizes that the care her daughter requires dictates "distributed mothering," and she calls upon what I would identify as othermothers to accomplish this

in her daughter's life (1999, 156). When othermothers participate in the narratives that disability constructs, the interdependence between the child with disability, the biological mother, and other caregivers becomes solidified. One of the women in Kittay's network of othermothers relays a sweet story of reciprocal learning between herself and Kittay's daughter, a story that Kittay uses to illustrate her idea of "care as labor and care as relationship" (157).

The demarcation between independence and dependence is generally determined by context, yet in this society we continue to subscribe to an either/or paradigm with little room for situations that don't fit either end of what is more likely a continuum between complete independence and dependence. The gray area of interdependency is rarely referred to in popular culture or in scholarship, but this is where most of us firmly live. This interdependency is often underacknowledged and can deprive caregivers, always giving and never receiving, of what they might need. Susan Wendell (1996, 142) discusses interdependency in light of an ethic of care and the reciprocity that it necessitates between the caregiver and the cared-for. While women who are mothers of children with disability are often privileged with this knowledge of interdependency and understand how it has constructed their experience of motherhood, othermothers should have access to this storyline as well.

Nurturing another human being can construct a woman as a mother, and the ability to nurture can construct a "good" or capable mother in the eyes of society as much as the perceived inability to nurture because of disability can steal the role of mother from a woman. Nancy Mairs struggles with this construction as she reflects on her diminishing capabilities due to multiple sclerosis. Although she does not want her children to become her caregivers, flipping the traditional roles, she recognizes that by allowing others to care for her, she can fulfill their need to be needed and thus reclaim the nurturing she desires to do. She concludes, "Permitting myself to be taken care of is, in fact, one of the ways I can take care of others" (1996, 83). She goes on to describe the power of her own storytelling as an act of caregiving, "Above all, I can still write, which for me has always been an act of oblation and nurturance: my means of taking the reader into my arms, holding a cup to her lips, stroking her

forehead, whispering jokes into her ears. . . . With such gestures, I am taking all the care I can" (84). In recognizing the interdependent nature of these constructed stories, we can better understand disability experience as well as the venerated occupation of mothering and how one can construct the other.

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