

**The politics of illness narratives:
Who tells, who listens and who cares?**

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Still reeling from the scene that had played out in the natural world, I moved inside to the workshop space, a wood paneled amphitheater. I had awakened that day to a light misty rain, an occurrence I hadn't thought possible in hot, dry Adelaide in February. Arriving at the conference venue, I could tell there was some consternation about whether the opening ceremony would need to be moved inside, even though all the arrangements were in place on the lawns.

Barb Wingard, a Nunga woman from Murray Bridge who was to be the keynote speaker, assured the conference collective that the weather would cooperate, and indeed it did. She gave her stirring opening address, there was a performance by an aboriginal troupe, a few short announcements and then, blam, the rain came pouring down.

My Western mind had no way of understanding the timing of the rain. Walking up the five flight of stairs to the amphitheater, I wondered how many people coming to the workshop on illness narratives would bring a Western mind and how many a mind shaped by other, non-Western influences? The rain/no rain event was auspicious. It raised the same question for me in the natural world that I wished to consider in the human realm. How do our ways of knowing influence the narratives we tell?

In my presentation, I focused on illness narratives, exploring ways we give meaning to our illnesses; ways we tell an illness narrative; the range of effects different kinds of illness narrative have; and the implications of this for caring for those who are ill or disabled. Although I have been writing about illness narratives for a decade, and speaking to large audiences about them for half that time, this was the first time I had made culture a primary filter for conceptualizing the development of and interpretation of illness narratives?

By ten after the hour, one hundred or so participants were in the room. Ireni Esler, a social worker from New Zealand, gave a lovely personal introduction to my work, trying to interest people in it and bring them at ease. I tried to continue in her vein.

"Good morning. How is this space for you? Are you comfortable? We cannot be outdoors, but the conference collective has given us these two huge flower arrangements to feast our eyes on. Please feel free to leave at any time you may need to, to move around, and to stretch.... I am going to do the best I can to make eye contact with you, but the lights are directly in my eyes and it is hard for me to see. I hope you will understand"

I spend time in the beginning of these workshops on illness narratives inviting people's embodied selves into the room and sharing my embodied self. The dominant discourse of workshops and conferences is that we are minds- in-space; no official recognition is given to our corporeal reality.¹ Many who attend my workshops are people for whom the body and its ills have been marginalized in painful ways, as hurtful as the discomfort the body's ills produce. I want to actively oppose, not replicate, those practices of marginalization.

Another way I oppose the marginalization of the body is to situate myself as a person who has been drawn to this topic because of my own illness journey. In doing so, I oppose another dominant cultural message, one that "asserts" that professionals should separate the personal and the professional. For me the personal is the professional and vice versa.

I am the daughter of a mother who died of cancer, a woman who has had breast cancer twice and the mother of a daughter who was born with a rare genetic disorder and who "came out" as a person with disabilities in 1996. These experiences have shaped who I am and what I bring to my professional life as surely as anything else has done so.

Finally, in setting the scene for my presentation, I honor my mother and my daughter. My mother, Violet Weingarten, wrote about her illness experience in 1975; her book, *Intimations of Mortality*, was published posthumously.ⁱⁱ My daughter, Miranda Eve Weingarten Worthen, has written about these issues with me and given me permission to speak about her.ⁱⁱⁱ The courage of these women envelops me; their insistence on voice inspires me.

Questions

I ask people to do personal work with each other on their own illness narratives or the illness narratives of someone they know well. It is asking a lot of people to launch into such personal subjects. One way I help people in the audience feel comfortable talking to strangers is to ground the theoretical concepts I present in my family's illness narrative. Another way is by asking questions of the audience about illness and disability so that people can see the range of illness experience shared by those who are in the room.

"Just to get an idea of the experiences of the people in the room regarding illness and family illness, I will ask a series of questions. I am referring to what is described traditionally as physical and mental illness. Please feel free not to raise your hand if to do so would require you to reveal more about yourself or your family and friends than you are comfortable doing."

1. How many of you have ever been ill for more than one month?

As a child?

As a teenager?

As an adult?

2. How many of you have lived with a person who has had an illness of more than one month's duration?

As a child?

As a teenager?

As an adult?

3. How many of you have been the primary caretaker of a person with an illness of more than one month's duration?

4. How many of you have lived with a person who had a disability -- physical, emotional or mental -- that impaired some aspect of his or her functioning?

As a child?

As a teenager?

As an adult?

5. How many of you have ever found it difficult to talk with other family members, friends or acquaintances about the experiences you have had as an ill person or about the experiences you have had caring for an ill person?

6. How often do you think people associate the words strong and independent with an ill or disabled person? Very common? Some of the time? rarely?

7. Thinking back to your own experiences with illness-- even the flu will do -- how many of you struggled with the temporary feelings of dependence or weakness?

These questions orient us to our own experience and to the experiences of those of us who have had illnesses and to those of us who have cared for persons with illnesses.

The Politics of Illness Narratives

The heart of my presentation is about the politics of illness narratives. Every illness or story has rules governing it: a politics. We all know that not all illnesses and conditions are the same. That is obvious. Most people however, are not aware that the narrative one can tell about an illness or disability is effected by certain parameters and that these parameters have real effects on the story, the story teller, and the people who listen to the story.

Again, I asked a series of questions. When I have asked them to North American audiences, I get fairly uniform responses. It shows me that there are a set of values and discourses about illness that are largely shared by audience members. I expected to get more variation in this audience and I was right. Some of the responses were counter-intuitive to me and required explanation by the participant. These are the kinds of responses that stretch me the most for they speak to experiences I haven't had or customs with which I am not familiar.

I asked the audience, as I would ask the reader, to think of one effect of these conditions on the story , the story teller or the audience to the story.

- If the illness or condition is widely understood?
- If etiology is known?

- If it is common?
- If there is treatment?
- If there is a cure?
- If there is no stigma attached?
- If it is inexpensive to treat or cure?
- If the illness itself produces no isolation?
- If the treatment of the illness requires no isolation?
- If there is no particular meaning attached to the illness or condition in one's ethnic group?
- If the incidence of the illness or condition is not related to factors of race, gender, class or ethnicity?

Now imagine the opposite conditions.

- If the illness or condition is **not** widely understood?
- If etiology is **not** known?
- If it is **not** common?
- If there is **no** treatment?
- If there is a **no** cure?
- If there is **no** stigma attached?
- If it is **expensive** to treat or cure?
- If the illness produces **isolation**?
- If treatment requires **isolation**?
- If there is **special meaning** attached to the illness or condition in one's ethnic group?
- If the incidence of the illness or condition is related to factors of **race, gender, class or ethnicity**?

Narrative Analysis

In the workshop, I then presented my own and my daughter's illness narrative to illustrate the concepts I will describe below. Our illness narratives reflect our class position in North America. We both have medical insurance that pays for the best standard of care. This promotes a belief that if there is treatment, one should accept it and try for a cure.

The events in our story would unfold very differently if we could not afford or had no access to quality medical care. For instance, if after feeling my first breast lump, I knew that treatment existed but I also knew that I would be unable to get it, my illness narrative would have evolved very differently. The points I make about illness narratives make sense in a particular cultural context.

The beauty of doing a workshop among people from a variety of cultural backgrounds, is that it is possible to draw on the range of experience in the room to place the theoretical points in cross-cultural perspective. For the purposes of this paper, I am abbreviating the personal story I told.

My partner, Hilary Worthen, and I became parents in the context of my mother's dying from a rare malignant tumor. Our first child, Ben was born six weeks before my mother died.

Miranda was born two years and nine months after Ben. She was diagnosed with Beckwith Wiedemann Syndrome at four hours of age by a pediatrician who had, by chance, delivered another baby with Beckwith Wiedemann Syndrome exactly one year before. (Later, we were to learn that at that time, 1979, there were only eight known children with Beckwith Wiedemann Syndrome in our region.)

Beckwith-Wiedemann Syndrome, or BWS, is caused by a mutation in chromosome 11 and most cases are thought to be sporadic as opposed to inherited. Infants with BWS usually have an enlarged tongue, abnormalities of the umbilicus, for instance omphalocele, and are atypically large. Many affected infants have

hypoglycemia at birth and it is speculated that this, if untreated, is responsible for the frequent occurrence of mental retardation. Children with BWS are at greater risk than the normal population of developing malignant tumors; of having enlarged internal organs; and of developing overgrowth of half of their limbs.

I was diagnosed with breast cancer in 1988, and then again in 1993. I have several relatives who have had breast cancer, and although their situations are not identical to mine, we can talk about shared aspects. While Miranda worries about the pervasiveness of breast cancer in her family, she is also aware that it produces a community of shared experience for me. This shared experience is missing for her because there is no one in the extended family who shares her condition.

Miranda looks "normal" but abnormal things happen to her, sometimes when she is just standing still. This can happen anywhere. Her joints dislocate easily. She often uses splints, braces or canes. She sometimes faints when she changes position from sitting to standing or lying down to sitting. As a young person, other children found this very odd and suspected her of faking. She has bad headaches that make her feel sick much of the time. Her inner organs don't function smoothly. She has many quirky ways of learning, although this has not prevented her from attending a selective university. Much of what happens to her body is uncommon. Even her learning difficulties are odd ones.

When her troubles began to accelerate during adolescence, we used externalization to separate her from BWS. This was a critical distinction in our family. BWS takes up a huge amount of our family energy and resources, but Miranda often gets lost in that and doesn't get much attention at all. We try to keep BWS in its place so that it doesn't take over Miranda's life or ours.

By the time Miranda was 16 years-old, externalization was insufficient to protect her from feeling bad about herself. Contacts with doctors who didn't understand her

troubles and didn't help, disappointments with friends who found her situation "weird," discouraged her.

One day, I was preparing to work with Michael White and some colleagues in New York and Miranda dislocated her hip sitting on the couch watching a football game with her father. I had to leave while her father took her to the hospital and kept me posted while I was away for two days. When I came back, I was desperate to help her. I stayed up all night thinking about what we could do.

This analysis started that wakeful night. It focuses on a comparison between my illness narrative, a breast cancer narrative, and her illness narrative, which is a BWS narrative. It focuses on differences in our experience that derive directly from the kind of story we can each tell. Though much can be explained by virtue of the different roles that we play in the family, the differential resources these roles give us access to, and the nature of the conditions themselves, we have felt certain that other parameters are at play.

By virtue of having a rare genetic disorder that virtually no one has ever heard of, Miranda is more isolated in her experience than I, who has a disease that affects one in eight women at some time in their life. At my age, it is hard to imagine that I might know or meet someone who does not know a woman who has had breast cancer. By contrast, it is hard to imagine that Miranda will ever find anyone who knows someone with her syndrome.

The disparity shows up in the health care community as well. In the twenty years that we have been interacting with the medical profession over concerns related to Miranda's syndrome, and we have easily consulted with or met 100 doctors, only a handful have ever personally worked with a child with Beckwith-Wiedemann Syndrome. By contrast, all my medical providers have other patients with breast cancer.

The difference translates into very particular experiences that we each have on a daily basis. I never feel alone. I know that there are many women and many families

who are going through what I have and my family has gone through, even right on my block! Miranda always feels alone.

Many people understand the etiology, pathophysiology and the course of my illness. If I go to my public library, I can find reference books and first person narratives, even my own book,^{iv} about living with breast cancer. No one understands Beckwith-Wiedemann Syndrome. It is a disorder with multiple manifestations which can affect a number of organ systems and no one can predict what is in store for any one person with the Syndrome. If Miranda goes to our public library, she will probably not be able to find even the name Beckwith-Wiedemann Syndrome in any of the 350, 000 books in the library.

The name I use to define my medical situation --breast cancer -- is defined as a disease and this fits with my experience of having had breast cancer. Each time I was diagnosed with breast cancer, the treatment that followed corresponded with my ideas of what having a disease entails. Though I had no pain from the lumps themselves, the surgery, chemotherapy, and radiation therapy I underwent confirmed my belief that I had a disease.

Miranda, on the other hand, carries a diagnosis that has no obvious implications. We know that she has BWS, but nothing inevitably follows from that diagnosis the way surgery, for example, follows from the diagnosis of breast cancer. When I told others I had breast cancer, most people could imagine what I was experiencing. When Miranda says she has Beckwith-Wiedemann Syndrome few people have any idea what that means for her.

Nor have we been able to find a word that conveys to us, much less to others, what she experiences routinely. Does she have a disease, an illness, a condition, a disability, a chronic disability, a chronic illness, a handicap, a disorder, a genetic disorder? We are baffled. No designation maps the territory. Without language,

experience dissolves. Without language, experience cannot be shared and community cannot be formed.

Drawing on narrative theory, we now use three concepts routinely to make sense of our experience.

These narrative concepts are not neutral but are loaded with cultural specificity. There are class, ethnic, religious, perhaps even national biases embedded into this classification schema. The schema has been very effective in making sense of our illness experiences. It has been effective in helping Miranda feel empowered in her life, both with friends and medical personnel. The schema obviously fits with values and discourses that shape our lives.

Narrative Concepts:

Narrative coherence

Narrative coherence is established by the interrelationships between plot, character roles, and themes or values. In an illness narrative the patient, the patient's family and medical personnel all play parts. With the diagnosis of breast cancer, a plot sequence unfolds according to fixed and known responses to data derived from the analysis of breast tissue. The patient will likely have visits with an oncologist, a radiotherapist, a surgeon and on-going relationships with them depending on how the plot unfolds. Family members can be given a likely set of events to expect. The feelings of everyone involved are likely to include sadness, anxiety, worry and fear. This was so for me. Though at any moment, I may have felt confused, the story I could tell was not particularly confusing. In fact, it was quite coherent.

By contrast, these elements applied within the context of Beckwith-Wiedemann Syndrome have the feeling of a deck of cards thrown into the wind. Having such scanty criteria available to us to guide our selection of cards -- choices -- it always feels just shy

of random that we are proceeding, playing, with one hand of cards and not another. The significance of any event is unknown, thus the plot unfolds chaotically. Nor is it clear who the players -- beside Miranda, Hilary and me, that is - should be. Do we go to a geneticist or a pediatrician? Do we find a specialist for each affected organ? How should we feel about it? Is this a disaster waiting to happen? Has a disaster already happened?

Narrative Closure:

The second feature of narrative that applies to illness narratives is that of narrative closure. One aspect of narrative closure is cultural resonance. The more familiar people are with the situation described, the higher the cultural resonance will be and the more likely that others will be able to participate with the person whose narrative it is in a way that supports, endorses and elaborates the story the person has to tell.

Breast cancer narratives have a high degree of cultural resonance. Within the last decade, there has been a very active breast cancer advocacy movement that has kept information about breast cancer highly visible to the public. It would be unthinkable today for a woman who has found a large breast lump have a friend or physician respond "Oh, gee, don't worry about that large lump." One way of conceptualizing why such a response is almost unimaginable today has to do with the high degree of cultural resonance breast cancer narratives have.

On the other extreme, Beckwith-Wiedemann Syndrome has low cultural resonance. Few people know how to respond when faced with the name of the disorder or even the names of the physical manifestations. Some people respond to their lack of knowledge with curiosity. Unfortunately, many more respond by withdrawing or operating from erroneous assumptions, wrongly generalizing from other situations. This occurs with lay and medical personnel alike.

Narrative Interdependence.

Narrative interdependence refers to the interrelatedness of one person's narrative to another's. In families, one member's narrative is usually interrelated to the narratives told by other family members. For better or worse, my breast cancer narrative is related to the stories other women in my family with breast cancer can and do tell. Miranda has her own story that relates to my breast cancer because, as the daughter of a mother with breast cancer, she worries about her own increased risk of acquiring breast cancer.

Miranda's illness narrative has no connection to the illnesses of anyone else in our extended family. Though Beckwith-Wiedemann Syndrome is genetic, she is the first person in the family to be affected by it. This probably means that in her case BWS is a new mutation that appears for the first time in her. However, along another dimension, neither Miranda nor I could tell an authentic account of our lives without reference to the illness experience of the other. In this sense, our illness narratives are profoundly interdependent.

Applications

In our lives, we have used this analysis in a wide variety of ways. It helps us explain responses we get from friends, family members and health care providers. It has been protective for us. It has also generated a number of specific coping strategies, several of which are described in a paper that Miranda and I published.^v

In this workshop, I asked each person to work in small groups and "to tell your own illness narrative or that of someone you know well. See whether these categories are useful to you in your storytelling. We have a wealth of stories in this room. See what we can learn together about the values and discourses that are embedded in these categories as ways of understanding illness. For instance, if you live in a culture in which scientific truth is not what it most highly valued, then are the effects of telling an incoherent illness narrative different than if science is valued highly? Is a coherent

illness narrative primarily important in a culture that places a high premium on scientific explanation?"

I circulated among many of the groups, listening as people applied this analysis, (and another set of narrative concepts that I had described,) to their own lives. After an hour, we returned to the larger group and people described what they had taken from the exercise.

It is not always easy for me to tell my own illness narrative and that of my daughter. Sometimes, it happens that a workshop or speaking engagement will coincide with a period in our lives when one or both of us is in significant distress. Telling our story takes on a poignancy that is almost unbearable.

The day I gave my presentation, I was in pain that was manageable. Hearing the stories in the small groups, talking with people in the large group about their experiences, participating in the proliferation of knowledges people have about themselves by providing language for the inarticulate body so that it too has voice, is the heart of meaning -making for me at this time in my life. It is doing what Miranda, aged sixteen-years-old, asked of the family and friends she invited to a ceremony to witness the history of her living with BWS: it is "nourishing hope and opposing despair."

I am profoundly grateful to have had the opportunity to share this work with so many people from all over the planet at this conference.

ⁱ This conference was an exception. The conference collective had set up two booths outdoors attended by two masseuses who were available each of the three days for short or long massages.

ⁱⁱ Weingarten, Violet. *Intimations of Mortality*. New York: Knopf, 1977.

ⁱⁱⁱ Weingarten, Kathy and Worthen, Miranda Eve Weingarten. "A narrative analysis of the illness experience of a mother and daughter." *Families*,

Systems, & Health: The Journal of Collaborative Family Health Care. 1997, 15:1, 41-54

^{iv} Weingarten, Kathy. *The Mother's Voice: Strengthening Intimacy in Families*. New York: Harcourt Brace, 1994.

^v See footnote iii above.