

**A Narrative Approach to Understanding the Illness Experiences
of a Mother and Daughter**

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Abstract

The authors, a mother and daughter, propose that a family's ability to cope with the illness of a member is mediated by the degree to which the illness is understood by the family's networks of health care, friendship and extended family. This factor has been given less attention than other factors, for example, the family member's role, the severity and chronicity of the illness, and the treatment regimen. The authors describe their own illness experiences, and their responses to the other's illness, in order to reveal differences in their illness experience along the parameter of how well their illnesses are understood. The authors introduce three narrative concepts -- narrative coherence, closure and interdependence -- to analyze their experience and to guide the development of coping strategies to mitigate the isolation of the daughter due to her illness. A ceremony of witnessing and the creation of a team to "oppose despair and nourish hope" are described.

We are a mother and daughter, the female half of a four-person family, and the half that does not live in reliable bodies. One of us, the mother, **Kaethe**, has had breast cancer. The other, the daughter, Miranda, age 16, was born with a rare genetic disorder

called Beckwith-Wiedemann Syndrome about which almost no one -- lay or professional person -- has ever heard.

Many factors contribute to a family's ability to cope with the illness of a member, including, for example, the family member's role, the severity and chronicity of the illness, and the treatment regimen. In this paper we would like to address another dimension. We believe that a family's ability to cope with an illness is also profoundly affected by the degree to which the illness is understood by the family's networks. We will discuss the impact of having a condition that is either poorly or well understood in terms of one's own ability to cope with it and one's ability to involve others in coping with the experience of disease.

We will contend that Miranda, by virtue of having a rare genetic disorder that is poorly understood, has more difficulty finding people -- professionals and friends -- with whom she can share her experience and that this produces an isolation quite different from **Kaethe's** experience. An important consequence of this difference is that the members of our family play a vital role in Miranda's developing understanding of herself, and that we are centrally involved in her construction of her story about herself.

Our approach to our subject is based on narrative theory, applied within a postmodern paradigm (Bruner, 1990; Griffith & Griffith, 1994; Sampson, 1993; White & Epston, 1990.) According to this paradigm, what we know we know with others. Reality isn't fixed, but rather is negotiated within the communities of which we are a part; meaning is primarily socially constructed. From this perspective, the self continually creates itself through narratives that include other people who are reciprocally woven into these narratives (Weingarten, 1991). This weaving together occurs through language, which doesn't represent reality but rather is constitutive of it.

A postmodern narrative approach emphasizes meaning-making as a key feature of human experience. As Jerome Bruner writes, “ By virtue of participation in culture, meaning is rendered *public* and *shared*. Our culturally adapted way of life depends upon shared meanings and shared concepts...” (1990, p.13). However, as we will make clear, we do not all have equal access to those meaning-making resources that facilitate the sharing of meaning. The difference in access to meaning-making resources profoundly influences the experience we have of our own illnesses and the experience others have of us. That is, differential access to meaning-making resources affects our weaving.

Although we will primarily discuss the way we are each woven into the other’s narrative of self in relation to our illnesses, the wider context of our lives is profoundly affected by the love and support we share with our husband/father and son/brother. These two men, in their own ways, make our lives possible. Hilary, my husband and Miranda’s father, plays multiple roles with us: physician, interpreter of other physicians, nurturer, inventor, driver, crisis manager, cook, and night duty nurse, among the many roles that could be enumerated. Ben, my son and Miranda’s brother, provides constant comfort with his generosity of spirit, fondness for play, willingness to share his friends with his family, and his easy-going approach to almost any of life’s contingencies.

ILLNESS IN AN EXTENDED FAMILIAL INTERGENERATIONAL CONTEXT

Because we are using our own illness experiences to illustrate the points that we are making, we think it will be useful to place our illness narratives in an intergenerational perspective (Chilman, Nunnally, & Fox, 1988; Eisenberg, Sutkin, & Jansen, 1984; Koocher & McDonald, 1992; Penn, 1983; Rolland, 1994; Walsh & Anderson, 1988; Walsh & McGoldrick, 1991). The first author will describe this history.

My husband, Hilary Worthen, a primary care physician and I, a clinical psychologist and family therapist, became parents in the context of my mother's dying from a rare malignant tumor. Our first child, Ben, was born 6 weeks before my mother died. Miranda, our second child, was born 2 years and 9 months after her brother. Her birth occurred 11 months after my father had a heart attack and 9 months after he underwent a complicated triple bypass.

Miranda was diagnosed with Beckwith-Wiedemann Syndrome at 4 hours of age. The pediatrician who had delivered her, by chance, had 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 (macroglossia), linear indentations of the ear lobes, 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 (hemihypertrophy).

During those 4 hours, before we learned that Miranda had BWS, I talked to family and friends, describing our new baby as beautiful and adorable -- as any new mother would -- and remarking on three features which later would become the cornerstones of a medical diagnosis. To my maternal eye, it was amazing that she was

full-term size 4 weeks early; I thought that she had the cutest little creases on her earlobes; and she kept her tongue at an angle outside her mouth, like a kitten about to lick a bowl of milk. I went on and on about these features, never once imagining that my rapturous descriptions of these three observed phenomena would be re-described by a medical language that would transform these already-beloved features from sources of joy to sources of worry (Kleinman, 1988).

I was diagnosed with breast cancer in 1988 and within the next year had multiple surgeries, chemotherapy, and radiation therapy. By that year, our children had had quite a lot of experience living with people who were being treated for cancer. Hilary's parents, who live in Vermont, were both diagnosed and treated for cancer in Boston. Both parents lived with us for the course of their treatments, a surgical recovery from stomach cancer for the children's grandmother and a 4-month course of surgery and radiation therapy for their grandfather.

The past 3 years have been the most difficult in Miranda's experience of living with her syndrome, though for us -- her father and me -- the first 6 years of her life were just as challenging. Additionally, Miranda, is deeply disturbed by the knowledge that many of her relatives have had cancer and several have had breast cancer. While she worries about the pervasiveness of cancer in her family, she is 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.

In this next section, we each recount aspects of our own experience living with, in **Kaethe's** case, breast cancer, and in Miranda's case, Beckwith-Wiedemann Syndrome. For each of us there is a natural separation of the narrative into three phases. We will

each respond briefly to the other's story, sharing how we have been affected by the other's condition.

In writing this section of the paper, we were amazed by how many ways we could tell any of the anecdotes we do in fact record here, and how complex the process was of selecting the ones we finally chose to create these particular narratives. We were struck that even when we are in control of the telling, rather than, for instance, when we are responding to the queries of health care providers, that we ourselves are often uncertain about which points are most important for us to stitch together into the fabric that becomes the story that constitutes our lives.

Living with Breast Cancer

Kaethe's version:

I was first diagnosed with breast cancer at age 42, in December of 1988. Ben was twelve and Miranda was nine-years-old. I learned of my diagnosis over the phone, in the middle of an afternoon that was already packed with carpools and grocery-shopping. In other words, breast cancer was invading my body, but it was interrupting the lives of my children as well as my own life, and of course, my husband's.

The visit to my surgeon with Hilary to review the diagnosis, prognosis, and probable treatment was followed by a tearful and then practical conversation about what to tell the children. There was something definitive and discrete to tell them. We knew what I had and we knew what would be done about it. We were in agreement to tell our children that night, but to go slowly, answering only the questions they asked. It was a tactic that worked for Ben and immediately failed for Miranda. She felt cut out of the

loop, confident that we knew things we weren't telling her and this, she told us, made her mad.

The evening was long and painful. Ben was warily optimistic, our parents supportive and devastated, and Miranda was typically laser-like in her probes.

That night, in bed, unable to sleep, Hilary and I talked and cried. I felt awful; I blamed myself for being the cause of our family's upheaval. It took hours before I was able to say that the cancer, not I, had been the agent of our sudden sorrow.

For me, the hardest role to fill as a person with cancer was that of mother. In that role, I was frequently in conflict with myself. A child wanted help with homework when I was desperate for a nap. A child had a school recital when I was scheduled for chemotherapy. I wanted to be alone when a child wanted to be close and cuddly. I rarely gave in to my wishes and for this I have mixed feelings. No one encouraged me to put my own needs first; I now believe, I was living out the precepts of the dominant cultural discourse about mothers: a "good" mother is selfless and a "bad" mother is selfish (Weingarten, 1994, 1995). The problem was that appropriate self-care didn't fit into the dichotomy and so was marginalized as an activity to which I could only aspire.

Fifteen months after treatment ended, in 1990, I made the decision to write about my experiences. The process of turning pain into prose was one of the most exciting times of my life. By placing my story out in the world, by hearing from so many people that my story had resonance with theirs, I created a community of understanding with many people beyond that of my health care providers, colleagues, family and friends.

Miranda's version

I remember when my mother first told me that she had cancer. We were in the den and I was on a huge brown wicker rocking chair that looked like it had wheels. I remember that my first impulse was to flip the chair over so that it would become like a rocket ship. I wanted to imagine that I was somewhere else. I don't remember anything else about that night.

I went through a metamorphosis that started when my mother was diagnosed and ended a few years later. I changed from being a loud, rambunctious child who was not afraid to ask for anything that I wanted -- the typical egocentric little child -- to being obsessed with giving my mother all the care she would tolerate, and then some. I became tuned into all her needs. For instance, I would massage her feet for long periods of time and would constantly pester her with hugs. I unconsciously chose to abandon those years of my childhood in favor of helping her.

Kaethe's Version

The second time I was diagnosed with breast cancer was 4 1/2 years later, in 1993. I was terribly disappointed, but not scared. The recurrence was local, my prognosis wouldn't change, I did not need chemotherapy, and I recovered well from surgery.

I felt fine about being without a breast. The aesthetics were even pleasing to me. When else had I had a chance to see a major asymmetry on my body? At 17, Ben was past the age when saying his mother had breast cancer or discussing mastectomies would have been embarrassing, but Miranda and her friends were not. My primary experience of this period followed the course of Miranda's adjustment from fear to rage to worry to uneasy acceptance. In this aspect, I would say that my response to having a breast

removed was less typical than Miranda's response. Most of my friends were shocked that I didn't fear "disfigurement," a concept that had no saliency for me.

Miranda's version

For the first two weeks I was furious at my mother. She had promised that she would tell me about any changes in her medical status because she knew that I felt most comfortable knowing all the facts. But this time, she had held out on me and didn't tell me until after the biopsy came back positive. Being enraged was a much better tactic than the one I had taken earlier, the one of internalizing my fear.

I was going to start high school in the fall and I was terrified that having a mother with only one breast would scare potential new friends away. I was convinced that my peers would be too insecure to understand rationally what had happened and that they would not want to be friends with me. I feared that I would be stigmatized as the daughter of a mutant.

My current friends validated my fears in one of the meetings of a mother/daughter group that we had. They too were frightened of what my mother would look like with her breast gone and with a huge scar in its place. She calmed their fears by showing them what it really looked like. They looked at her ready to submerge their faces in the intact chests of their own mothers. I looked at them and then at her with a mixture of awe and pride.

That was a major turning point for me. Through conversations with my mother, I was able to transmute my fear of her rejection by society into political action. I learned to speak out against the overwhelming oppression of "lookism," an excessive, but culturally determined, concern with appearance (Pipher, 1994).

Kaethe's version

Since my mastectomy in 1993, I have continued to develop appropriate denial and to increase my capacity to manage worry and fear. The most painful times are listening to Miranda's fear and the hardest not letting my guilt intrude on us. A few months ago, I asked her to think of a present in the \$100 dollar range that she might like for her 17th birthday present. She wasn't joking when she announced to Hilary and me that she wanted a mammogram. I am fortunate that she is so present to her feelings, so articulate and passionate about them, and so willing to share them with us.

Miranda's version

My life has been hijacked by fear of breast cancer. I think about it almost every day and often become terrified. I wrote these paragraphs a few months ago after one of these terrified moments:

“This evening one of those fears overtook me again. I was sitting in one of our comfortable living room chairs talking about health issues when the veil came toward me. I wanted to run out of the room, to say something totally non-sequitur, anything to avoid talking about cancer. I didn't though. If anything I perpetuated the conversation more by relating my own views and asking questions. In the midst of people who I feel know me the best and nurture me the most, I felt alone and scared.

“A black cloak was hovering over my head about to pounce on me and envelope me in terrifying darkness. Not the beautiful darkness of a starless night, but that darkness that exists when all feeling is taken away and all that exists is the void. I wanted to cry, I was so scared of this impending shroud, but I couldn't. I was anxious that crying would

stop the conversation and I would never hear what I wanted to hear, but knew would be harmful for me to hear. It was like a gruesome accident on the highway; you don't want to look, but you can't take your eyes off it."

Living with Beckwith-Wiedemann Syndrome

Miranda's version

Though my life from its earliest point has been affected by having Beckwith-Wiedeman Syndrome, it is hard to say how I felt about it before I had my own consciousness of it. Most of my information about the earliest part of my life in relation to BWS comes from my parents.

I was always the kid in my elementary school who had a cast on her foot or her arm, or a bandage around her knee. I was proud to say that I had "broken, sprained or dislocated over forty bones." I never thought of these as fitting under one umbrella problem, other than my "rambunctiousness" which was the term my orthopedist (or as we jokingly called him, my primary care doctor) used for me. I now know that all of these were probably related to BWS.

There were other early manifestations of BWS that I wasn't proud of but rather made me confused and embarrassed. Some of these were noticeable to other people -- like the size of my tongue and my jaw -- and I was teased about them. Others I could keep hidden, but they still made me feel inadequate.

It was only last year that I asked my mother to tell me about her experience of my birth and first few years of life. Up until then I had been content with knowing simply that I was diagnosed with this syndrome 4 hours after I was born; that they thought I was

going to die; that my father fed me all night so I wouldn't die; and that my grandfather talked with my mom about the importance of taking the risk of loving me wholeheartedly.

Kaethe's version

We did learn that Miranda had BWS 4 hours after she was born. We were told a worst case scenario: she might be retarded; have malignancies of the internal organs; and asymmetries of her limbs. Hardest of all to hear was that the doctors were uncertain that she would live. This uncertainty lasted for 3 months when she was seen by a specialist who informed us that Miranda had never been at risk of dying, though some infants with BWS are.

The first few weeks were an overwhelming melange of falling in love and living in terror. Many doctors saw Miranda and seemed to take delight in being the first doctor to tell us something else was "wrong." We soon learned that many doctors were extrapolating from similar but not identical medical conditions and that these extrapolations were often wrong. Because the BWS narrative has so many gaps, doctors filled in as best as they could, often with unintended consequences. One pediatric fellow told us that Miranda would be unable to integrate stimulation from more than one sensory channel at a time. He advised us never, for instance, to talk to and touch her at the same time. Further, he told us that it would be unwise for her to have contact with her older brother until she herself was older and could handle the stimulation. Though distressed by the possibility that we were harming her, we refused to accept his clinical assessment as valid since the consequences for normal baby care and family life would have been calamitous.

The early years with Miranda were full of contradictions. The story we told her about her birth and early years was an expurgated one. By 6 or 7, she had a version of her life that emphasized heroic elements. We made her larger than life to compensate, I suppose, for our fear that she would have no life. We made her a heroine; a baby whose life force was so strong that she defied the doctors' predictions that she would die.

The actual story was filled with confusion, pain, hard work and some courage. Hilary and I tried to get the best help that we could, evaluated the recommendations we received against our own growing knowledge of BWS and then selected assessments, procedures and treatments that made sense to us. It was lonely, scary and isolating most of the time. Friends and family supported us but could not immerse themselves in the level of detail that would have been required to help us. Only our pediatrician, Dr. Patricio Vives, walked the walk with us. His wisdom and compassion have sustained us since Miranda was 6 when we had the good fortune to begin working with him.

Miranda's version

When I was nine, my parents gave me words to help explain my experience and to help me understand that I was not at fault for some of the problems that I was encountering. The words were "Beckwith-Wiedemann Syndrome" and I had never heard them before. They had the immediate effect of assuaging my feelings of stupidity and inadequacy, but I forgot them almost immediately after they had worked their magic.

It was 3 years later before I actually connected my life to BWS. I was being evaluated for braces and my socially incompetent dentist told me that on a scale of one to ten where ten was the worst possible dental situation, I was an eleven. As a person who dutifully brushed her teeth twice a day and whose older brother had been told that his bite

was “perfect,” I was aghast. I asked him why and he replied boldly that it was because I had BWS. Later, I found out that it was written all over my chart that I didn’t know about BWS and that I was not to be told anything about it. The dentist’s speaking upset me profoundly, and it made me conscious of having BWS in a way that I never had been before.

I know I connected with it then because one month later, at my school picnic, I was unable to participate in my last school race because of Achilles tendonitis. Before I would have just left it at that. But I remember thinking I couldn’t run because of my syndrome.

Kaethe’s version

Throughout Miranda’s life, Hilary and I regularly discussed what we should tell her about the physical problems she was having. In a family in which truth is valued alongside love, and honesty is taken for granted, we never lied to her and never told all there was to tell. Our early strategy was to treat each event singly and give her the best explanation we could for whatever problem she was having. After all, we couldn’t tell her anything that would be coherent and if she asked us questions she too would have to live with the uncertainties that the gaps in knowledge and therefore storying produced.

By the time Miranda was 9, it had become clear that our effort to spare her a “label” was spinning off other problems. She blamed herself for physical difficulties that we knew were not under her control. We felt she needed to know about BWS, but we hoped she wouldn’t weave it into her developing sense of personhood. We told her a story of BWS that embellished the birth story she already knew with some additional

elements. We explained further that BWS affected many parts of the body and that BWS, not she, was responsible for most of her injuries and difficulties.

We would never have been able to predict the effect on her. She seemed instantly and immediately relieved to know there was a “reason” and yet the reason itself seemed to disappear from her awareness. She never asked us questions about BWS and never used the term herself.

The episode with her dentist at age 12 was pivotal for me too. I had been unable to protect her although I had been sitting next to her and was signaling wildly to the dentist. She left the dentist distraught. Comforting her as best I could, I realized that my more important task was to help her access her own resources to make herself feel better.

Miranda's version

The last three years have been very difficult for me. First, the symptoms of BWS have been worse than I can ever remember. I suffer pain most of the time, whether from headaches, joint dislocations, or other problems related to abnormal formations of my internal organs. Because I spend my time thinking about matters that are very different from my peers, I am alienated from them. I am occupied with evaluating levels of pain, not spring colors. I'm continually thinking whether I want to share anything of my situation and with whom. I am constantly trying to figure out what I need to report and what I don't. I am trying to avoid saturating my parents with my medical complaints and yet still be honest about what I feel.

My peers often ask me what is wrong with me. They notice that I have been absent for long periods of time and that I often come to school on crutches, with body braces or with slings. I have to decide whether to tell them the whole truth or not. When

I have made the decision to tell people, the outcome has not always been positive for me. Some people have been grossed out by what I have told them and others have not kept my confidence and instead repeated what I've said to people I wouldn't have told myself.

This year, I was hospitalized several times. I used to love going to the hospital because I felt safe there. I felt that the doctors were there for the sole purpose of taking care of me and making me feel better. This year, for the first time, doctors questioned my honesty. In a situation in which there was great uncertainty about the cause of my pain, several doctors accused me of not reporting my symptoms accurately. I realize now that having an unusual condition is going to set me up for disbelief. In the face of their lack of knowledge, they took the easy way out and blamed me, relying on a psychological explanation to fill in the gap in the story because they didn't have a satisfactory medical explanation. Fortunately, I had the unconditional trust of my parents and my pediatrician who got me to other doctors who finally diagnosed the problem and prescribed appropriate treatment.

I am struggling not to let BWS take over my identity, but to be only a part of it. At the same time, I am trying to expand the category of what a disabled person looks like. When Gloria Steinem turned 40, reporters were disbelieving that a woman looking so young could be 40. She said, "This is what 40 looks like." I am trying to do what she did when people doubt my having a disability. I say, whether outloud or to myself, "This is what a disabled person looks like." I am trying to identify myself with a group of people -- disabled people -- who are not the same as I am but who have had similar experiences. I am not going to lose myself in their experiences but I am going to use them to build my knowledge of myself and my own experience.

Kaethe's version

The last few years have been as hard in their own way as were the first few years. What makes them different is that Miranda is an active participant and collaborator in the decisions that we must make. We are blessed by the fact that she is such a careful and accurate reporter of her experience.

When she is having a great many symptoms, the family focus narrows to get through the crisis. We are on the phone constantly with family and friends who want updates and want to offer support; we are scheduling and going to see doctors; coordinating with her school; keeping our son Ben, who is in college, in touch with what is happening; and trying to make Miranda more comfortable. Sometimes she requires 24-hour face to face care.

All of this usually takes place within a context of uncertainty: we often don't know what's going on and what to do about it. A dramatic example of this occurred in March, 1995 when Miranda injured her hip while sitting on a couch and then dislocated both shoulders the next day from using the crutches she was prescribed. We were pretty sure that BWS was responsible for the shoulder dislocations, but the hip? And, what had happened to the hip? More importantly, could it happen again? None of these questions have ever been resolved.

THE ILLNESS EXPERIENCE

A Narrative Analysis

In the last few years, Miranda and I have tried to understand the differences in our two illness experiences and the impact of these differences on our family. 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. We have begun to attend to features of the stories we tell about our conditions and we notice that there are significant differences in our experience that derive directly from the kind of story we can each tell.

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, because I have a disease that affects one in eight women at some time in their life (Brack & Brack, 1990; Butler & Rosenblum, 1991; Hargrove, 1988; Lorde, 1980; Weingarten, 1994; Whitman, 1993). 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 17 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 5 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. In her world, she is an N of one.

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, about living with breast cancer. No one understands Beckwith-Wiedemann Syndrome. It is a disorder with multiple manifestations that 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 lump itself, 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.

In the last few years, since Miranda's physical condition has worsened, it has become imperative to us to find concepts to express the significance of these

phenomenological differences between us, to make sense of certain reliable differences in our illness experiences. Drawing on narrative theory, we have located three concepts that we now use routinely to make sense of our experience. These concepts have provided the stepping off point for the development of a set of coping strategies that have been invaluable for both us. First, we will present these concepts. Next, we will describe the coping strategies that have derived from our application of these concepts to our illness experiences.

Narrative Concepts

Three characteristics of narrative have relevance to understanding illness experience. These three characteristics are narrative coherence, narrative closure, and narrative interdependence (Chatman, 1978; Weingarten & Cobb, 1995).

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, the 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? Are we on the edge of a cliff or have we fallen over? We have never known, and no one has ever been able to tell us either.

Narrative Closure:

The second feature of narrative that applies to illness narratives is that of narrative closure. Narrative closure occurs when the story that is told seems to have only one way of understanding it. That is, the story resists alternative interpretation. There are two elements that help create narrative closure: completeness and cultural resonance. With regard to completeness, the more “open” the story, that is, the more the story has gaps, the more vulnerable the story is to others filling in these gaps with material of their own. With regard to 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 narrative closure: they resist alternative interpretation because the course of the disease is so well known. For

instance, how commonly do you think a woman who has found a large breast lump would find a friend or physician who says “Oh, gee, don’t worry about that large lump you have”? One reason such a response is almost unthinkable these days is precisely because so much is known in both the lay and professional communities about breast cancer. There is high cultural resonance.

On the other hand, Beckwith-Wiedemann Syndrome has a low degree of narrative closure. There are multiple gaps in the story and virtually no cultural resonance. Few people know how to respond when faced with the name of the disorder or even the names of the physical manifestations. For instance, as we mentioned, an enlarged tongue (macroglossia) was an early diagnostic feature. Some people associate an enlarged tongue with children who are mentally retarded, some of whom indeed do have large tongues. Our inability to tell anyone what Miranda’s large tongue meant led some people to assume she was retarded! The story - her story, our story -- had, has gaps -- just about everywhere -- and people fill them in as best they can. This has occurred with medical personnel as well.

Narrative Interdependence.

Finally, 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.

COPING STRATEGIES BASED ON A NARRATIVE ANALYSIS

I had been in New York at a professional conference the days that Miranda dislocated her hip and shoulders. Hilary kept me posted by phone and each time I checked my phone messages, there was a long, detailed and excruciating message about her situation. I realized how impossible my life would be without Hilary; how fortunate we are that we collaborate about her care, functioning like a precision team. I also realized that I had to glean from my own illness experience those elements that made living with it relatively manageable and find a way to graft these into Miranda's illness experience

The evening I returned, I was unable to sleep. Miranda was in considerable pain, but only the three of us and Ben knew it. Ben called from college daily, but no one else in our network or hers knew. She was in too much pain to consider talking to others and we were working so hard at the practical matters of tending to her, taking her to her various appointments, and trying to squeeze in our work that we were, this time, as we often were, isolated from any support.

Partially, I knew that the difficulty of responding to people's questions each time -- Why did it happen? -- was exhausting and frustrating. We never had explanations that were satisfying, to us or to others. Thinking through the narrative categories that I use in my work, the ones I have described above, I realized that we had to find a way to create legitimacy for the narrative we could tell-- coherent or not; that we had to find a way to increase the cultural resonance of Miranda's story, to decrease her sense of isolation, even if it were to a small "local" group of people who could share our "cultural" meanings; that her story had to link to those of others, both by creating an audience for hers and by finding a community of like-situated persons; and finally, she had to feel empowered about as many aspects of her situation as possible.

The next evening I proposed to Miranda that we design a ceremony and invite a group of friends and helpers whom she would trust to share the history of her living with Beckwith-Wiedemann Syndrome. I shared with her the rationale for this suggestion and she immediately accepted it.

Miranda's Version

My mother's suggestion really made me aware of just how isolated I was. The idea of a ceremony was relieving. I had hope that I could feel connected to others.

Kaethe's Version

Miranda and I designed the invitation and the ceremony itself. On the invitation we explicitly asked people to join a team for her, one that would "oppose despair and nourish hope." Those were her words. The ceremony, we hoped, would help shift her relationship to Beckwith-Wiedemann Syndrome, from one in which she was isolated

from others to one in which others could support her. We hoped that by describing the effects of BWS on her life, “unmasking” these effects (White, 1995; White & Epston, 1990), she would find others willing to help her live with BWS.

Miranda’s Version

I designed two rituals that were important to me. The first ritual involved candles. At the beginning of the ceremony, I gave each of the twelve people present a candle and I lit the one in front of me. I began to tell the story of my living with BWS. I asked people to light their candle from mine when they understood the magnitude of my experience. As people lit their candles from mine, at different intervals of time, I felt that each lit candle took some of the burden off me.

The second ritual I designed was intended to show the feelings that BWS makes me have. I listed about 30 different feelings on small cards, some of which were positive and some of which were negative. I had purchased two beautiful boxes and selected one for the negative feelings and one for the positive feelings. This was my way of honoring my negative feelings but also to have a place for them outside my heart. I asked people to brainstorm with me some other positive feelings that they thought that they could help me feel through their participation on my team. People suggested many words, like “wise” “humorous” “connected” “loved” and “content.” I felt understood and I felt it was possible that they could help me feel these ways.

Kaethe’s Version

The effects of the ceremony have been profound and long-lasting. She does have a team. Ten women check in with her regularly, can be counted on in crises, and know

her story. The difficulty of explaining has dissolved because they all know how slippery BWS is and they no longer ask questions that make us feel stupid or ashamed when we can't answer them. Nor do they challenge whether or not Miranda is really in pain. They accept, as we have years ago, that the "rules" of BWS are shifty and that while the experience of pain is the "most vibrant example of what it is to 'have certainty' ...for the other person it is so elusive that 'hearing about pain' may exist as the primary model of what it is 'to have doubt'" (Scarry, 1985).

Following the ceremony, we created documents that better represent the history of her living with BWS (White, 1995). I wrote for her medical records to every hospital and medical office where she had been seen and together we compiled a chronology of medical events -- still with some missing pieces, I'm afraid. We also decided to attack head on the problem of those routine problem check lists that she finds so frustrating because the categories rarely allow her to make check marks on the page, thus rendering invisible the reality of her particular physical problems. Instead, we designed a problem check list that counts as categories those that fit her problems. She now takes this form to every first visit with a new doctor.

Finally, she has begun to read first person accounts of disabled people and read accounts of the history of the disability rights movement in this country (Bow, 1992; Grealey, 1994; Merker, 1992; Panzarino, 1994; Resnick, 1984; Saxton & Howe, 1987; Shapiro, 1993; Sontag, 1977; Weingarten, 1977; Williams, 1992, 1994; Zola, 1983). Her sense of community has shifted.

Miranda's Version

Reading other person's accounts of their challenges in life has been both oppressive and liberating. At times, I have felt swamped by sadness but at other times I have felt astonished that other people could have experiences so similar to mine. It makes me think that I can be walking down the street and the person walking next to me might have had experiences like mine at some point in his or her life. I feel much less isolated than I did before.

CONCLUSION

From a narrative perspective, empowerment is related to one person experiencing another person as accepting and elaborating what she has to say without challenging the basic integrity of her story (Cobb, 1992; Weingarten & Cobb, 1995). In this last year, not only has Miranda experienced others' speaking which has elaborated hers without challenging its basic integrity, she has spoken out to stop medical people from speaking in ways that do not empower her and she has spoken up for others in ways that empower them. Armed with the knowledge that her condition, unlike mine, will rarely be automatically understood, she knows that she must work harder to gain others' understanding. Also, she has learned that she must be always prepared to stop people from drawing false conclusions about her. Writing this paper, is one more step in developing a more collaborative relationship with BWS, showing that she has expert knowledge about it, and empowering herself.

We believe that the empowerment of all members of a family is fundamental to their coping with medical crises. Health care providers have the opportunity at all times to cut short, to interrupt, to contradict, to take over or, alternatively, to respect and to

elaborate the illness narratives that family members and the designated patient tell. We hope that this paper will strengthen your resolves to act in ways that endorse and elaborate and ultimately empower the people with whom you work. We hope that our writing will have created possibilities of empowerment for people who may now be better understood because of what you have read.

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