
CHAPTER 27

Multiple Sclerosis, Beliefs, and Families: Professional and Personal Stories of Suffering and Strength

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I HAVE HAD SOME profound personal shaping experiences with illness: as a child, as a novice health professional, and as a middle-aged daughter and experienced health professional. One of these experiences has been with my mother's chronic condition of multiple sclerosis (MS). These experiences have left me more compassionate and, I believe, more passionate about being helpful when collaborating and consulting with families about their difficulties with illness.

In addition to experiences with illness that have shaped me personally, I have also had many shaping experiences in my professional life. These personal and professional experiences have shaped my current beliefs about illness and family functioning. I have come to firmly believe that "beliefs" shape our experience with illness far more than the disease itself. Beliefs exist not only in the domain of meaning but also in the domain of emotion and behavior. I have also come to realize that beliefs can even influence cellular functioning.

I grew up in Canada with my maternal grandmother, mother, father, and younger brother. We were a true-blue Anglo-Saxon family. My maternal grand-

parents immigrated to Canada from England. My paternal heritage, although some five generations in Canada, is originally Scottish. My English maternal grandmother who lived with us suffered from chronic arthritis. She had tremendous status in our family by filling the role of "mother" by day while my mother worked outside of the home with my father in our family business.

I learned in my childhood years how chronic illness becomes a family member. I observed and learned about the suffering that one can experience from chronic pain, both firsthand as I saw my grandmother suffer and secondhand as I emotionally suffered for her. I also learned how chronic pain controls the lives of all family members, determining, for example, how well my brother and I behaved on any given day, how much my grandmother was able to "mother," and how we as children were invited to be more compassionate because of having a pain sufferer in the family. My grandmother was the center of our family, but the chronic pain she suffered ruled even her.

Although I have had other illness experiences over the years with friends, friends' parents, and my grandparents, another profound shaping experience has occurred over this past year and a half. I have been intensely involved in the illness experiences of my parents, predominantly my mother. At age 49, my mother was diagnosed with MS. However, until a year ago, she had experienced only minor symptoms, such as occasional numbness in her legs and arms. Consequently, she enjoyed an extended remission for some 24 years. Now, at 73, my mother has experienced six major exacerbations over the past year. She has been hospitalized four times, two of those times for more than two months. Each exacerbation has left my mother, who has led a very active life, more physically disabled. Through this time, I have witnessed my father become a very caring "nurse" and husband while his own life has become very constrained; my sister-in-law does the work of a saint with her many caretaking kindnesses; and my brother has shown thoughtfulness and creativity in his ideas about healthcare for our parents. At this moment, each member of my family has many illness stories as we again opened the door to the long haul of chronic illness.

The extreme MS exacerbations left my mother unable to walk, feed herself, or control her bowels and bladder. But with much courage, strength, and determination, she crawled back, metaphorically speaking, to being able to feed herself with her unaffected arm, walk a few steps, and once again have control of bladder and bowel functioning. These extreme exacerbations of MS also brought on the additional burden of chronic fatigue and weepiness. With each exacerbation, my mother never returned to the level of either physical or cognitive functioning that she had previously enjoyed. Currently, one of the most demoralizing aspects of this disease is the chronic pain my mother suffers in her left arm and hand.

Despite all these setbacks, there is good news to tell. My mother has now been out of hospital for four months. We believe she is doing well owing in large part to the introduction of a new drug, Betaseron, which seems to have controlled the exacerbations for the moment. We also believe her well-being is due to her incredible determination, and my father's, to have her return home. However, if not for my father's caregiving, my mother would have to be in some type of permanent care. While my mother's spirits are presently very good and she receives

very good physical care, her condition has had a profound impact on my elderly father's health. For the past six months, he has been suffering chronic pain from herpes zoster (shingles is triggered by stress).

One of the most painful aspects of this past year is the total incongruence and dissonance between my life as a professional and my life as a family member. My professional life is devoted to teaching, writing, presenting, researching, and doing clinical work about helping families cope with illness. In my personal life, not one health professional has asked me how I am experiencing my mother's chronic illness or what impact it has had on my life or my family's. Worse yet, not one health professional has asked these questions of either my mother or father. Nor have any other questions been asked of my parents about the impact of MS on their marriage of 54 years. The care by health professionals for my mother's physical suffering from this disease has been adequate, most of the time. But the emotional suffering has never been addressed by any health professional.

I have also been astounded and filled with anguish over how invisible I have been made to feel during my hospital visits—most of the nurses and physicians have not even given me eye contact, let alone spoken to me. I have always had to be the one to introduce myself to the health professionals caring for my mother, even when I've been sitting right at her bedside. Being rendered invisible erased my existence in the illness experience, causing much dissonance and leaving me suffering emotionally.

Multiple sclerosis is a disease that affects the white matter (myelin sheath) of the central nervous system (CNS) and/or the stem of the brain. The cruellest part of this disease is that it invades some of the most vital aspects of a person's functioning: cognitive, sensory, and motor. Any description of MS as a disease doesn't begin to describe the anguish, despair, and upheaval it brings to a person's life, and to the lives of the people with whom they live and love.

The beliefs we hold about illness are at the heart of health and healing. My colleagues and I previously have written about the usefulness of focusing on beliefs in describing our clinical work with families experiencing hypertension (Duhamel, Watson, & Wright, 1994); family violence (Robinson, Wright, & Watson, 1994); osteophytes and chronic pain (Watson, Bell, & Wright, 1992); cancer (Wright & Nagy, 1993); epilepsy (Wright & Simpson, 1991); angina (Wright & Watson, 1988); cardiac illness (Wright, Bell, & Rock, 1989; Wright, Bell, Watson, & Tapp, 1995); and the impact of loss by suicide (Watson & Lee, 1993). Most recently, we have completed a book entitled *Beliefs: The Heart of Healing in Families and Illness* (Wright, Watson, & Bell, 1996), which describes, in much depth and breath, our advanced practice model.

CLINICAL EXEMPLAR: THE DUAL ROLE OF "NURSE" AND FAMILY MEMBER

Twelve years ago, I had the privilege of working with a young family with three members: Robert, the 34-year-old husband/father; Cathy, the 33-year-old wife/mother; and their 5-year-old son. Cathy was experiencing MS. She had been diagnosed some seven years earlier, but the MS was now rapidly taking over her body. Despite the deterioration of her body, this young woman expressed with great articulateness and emotion her lack of satisfaction with her sexual relationship with her husband. Cathy stated very clearly that she desired more sexual intercourse in their marriage. Robert explained that he felt more like a nurse than a husband and that consequently he did not find his wife as sexually appealing. For example, he shaved his wife's legs and underarms, helped her on and off the toilet, and bathed her.

During this very moving therapeutic conversation, I explored with the young couple their beliefs about the role of family members in their illness experience and asked whether they would be open to others assisting with the nursing care so that Robert could be more of a husband. They were able to suggest a friend of Cathy's who would be willing to assist with some of the nursing, like shaving her legs and arms and bathing her from time to time. This simple intervention not only improved their sexual relations but also enabled Robert to have more short moments of respite from the total responsibility of caring for his wife as her "nurse."

I learned much from this family about the importance of exploring the beliefs of family members in their caretaking roles and how the dual roles that family members experience as "nurse" and family member can create familial stress and conflict. What I've learned has helped immensely not only in my professional experiences with other families but in my illness experience with my own family. After my mother's last discharge from hospital, I explored my father's beliefs about his role in my mother's care and asked whether he would be open to home care services. His response was, "What can a home care nurse do that I can't do?" I assured him that there was nothing she could do that he couldn't, but I also pointed out that home care would provide an opportunity for him to have some brief periods of respite from being a nurse. He eventually did open up to the idea of having home care and now relishes the three half-days a week when he is relieved from being a nurse and can enjoy being a husband.

CLINICAL EXEMPLAR: THE SON TAKES LEADERSHIP AND THE PARENTS TAKE A HOLIDAY

Six years ago, I had the privilege of meeting a remarkable family of three. They had referred themselves to our outpatient clinic, the Family Nurs-

ing Unit, at the University of Calgary. In the first meeting with the family, I met Dorothy and Henry. They had moved to Calgary from an eastern city of Canada to care for Sam, their 34-year-old son who was experiencing MS. They explained to me that they moved here rather than have their son return to eastern Canada because Sam, their only child, "liked the doctors here" and "had a house here."

I consulted with this family for four sessions over a period of six months—two sessions with the parents, and two sessions with the parents and son together. The outcome was quite gratifying. To my question of "What brings you here?" the parents responded that "there are tensions in the home, and we don't know how to cope." When I asked my "one-question question" in the first session—"If there were just one question you could have answered during our work together, what would that one question be?" (Wright, 1989)—the parents responded, "How can we get a break?" They had the constraining belief that to have any respite together was unfair to their son, who wasn't able to have a holiday; they didn't know whether he would be in favor of them going on a trip. They also worried about who would care for him in their absence.

In our first meeting together, I also asked these very devoted parents what their understanding was of MS. They explained that they had not been informed at all about this disease by health professionals. Six months following diagnosis, Dorothy called the MS society and obtained brochures and a book. She offered her belief that when someone is newly diagnosed, his or her "parents should be contacted and have it explained."

This was reminiscent of my own situation with my mother's MS. From my clinical practice and research, I have come to believe that talking about the illness experience and being able to obtain information and ask questions can alleviate suffering. Consequently, I arranged for a family meeting during one of my mother's hospitalizations with a professional from the MS society. He came and explained MS to me and my family and outlined the resources available. I don't know how much any of us absorbed or understood that day, but the visual impact of my mother, father, brother, nephew, and me sitting together talking about MS with a health professional made me believe, for a few precious minutes, that MS was smaller and had less strength than we did.

It is imperative to draw forth and understand family members' beliefs about why they are encountering an illness experience in their lives. What one believes about the etiology of an illness dictates what healing and treatment one will accept. In my clinical work with Sam, I asked a question about his illness experience in order to draw forth his beliefs about how MS had affected his life. Note that this one question immediately drew forth intense affect as this young man's silent tears gave evidence to his grief about his illness. What followed was a very important and profoundly moving discussion about his explanation of his illness.

WRIGHT: What's been the biggest surprise to you about it all?

SAM: I don't know, it's kinda hard to believe you could have 29 . . . (*begins to weep*) 29 good years . . . (*long pause*)

WRIGHT: And then some, not so good years now, yes? (*Sam nods his head.*)
Do you see these as not good years?

SAM (*crying*): Yes.

WRIGHT: Well, it's like I've said, you've been dealt a challenge and a blow in your life, Sam, that most people do not have to face. And I can appreciate that must be a real struggle for you. How do you make sense out of that for yourself? What thoughts do you have about why you and not other people? How come other people haven't been faced with this challenge in their life? How have you answered that for yourself?

SAM: There's not really any logical explanation for it. It's just the odds or the luck of the draw or whatever.

WRIGHT: It's always one of the things that people really struggle with, I find—especially young people when they have been diagnosed with a serious illness and experience a serious chronic illness— . . .

SAM: Yeah.

WRIGHT: . . . is trying to make sense out of it for themselves, you know, trying to understand, and they have many different beliefs about it. I'm wondering what your belief is about how is it that you have MS?

SAM: There's not really any explanation, I guess. And no one in our family has it.

HENRY: No.

SAM: On either side of your families.

HENRY: That's right.

WRIGHT: So how do you explain it, the luck of the draw? You had a stroke of bad luck, is that what you say to yourself? Anything else you say to yourself about it?

SAM: Not really (*pauses*). I can't really rationalize . . .

The expression of Sam's grief was validated, and I also made a connection: Grief is tied to our belief about the cause. It could be speculated that Sam's belief that it was "the luck of the draw" perhaps caused him more grief because this made his MS so very much out of his control. This was a very different explanation from that of his parents, who believed that the MS was the result of a virus or measles when he was a boy.

His belief that MS occurred in his life because it was the "luck of the draw" also had implications for how he would live alongside his illness. One striking example of an influential cultural belief that dictates much of how well we live alongside illness is the high value placed on control. This predominant cultural belief ignores the spiritual and subjective sides of the illness experience. Consequently, I have found it useful to offer the option of "living alongside of illness" as another way to deal with illness besides the polarized "control" or "eliminate" options. Asking family members whether they would like to control, overcome, or live

alongside of illness often increases a person's options in handling the control issue and frequently provides an escape from the cultural belief that the only way to manage an illness is to control it.

A heart-to-heart conversation between Sam and me later proved to be a turning point in this young man's healing from his intense emotional suffering. His parents reported in the final session that they believed that one of the most useful aspects of the sessions was having their son talk about his illness experience, something they claimed he had never done before. The intense affective sharing began when I drew a distinction between possible affective responses to illness, specifically anger versus sadness:

WRIGHT: Do you ever get, I mean, obviously I see you get sad, about your MS? Do you ever get angry about having MS? (*Sam nods yes.*) Which emotion is more common for you to feel about your MS? Do you feel more sad or more angry about it?

SAM: Sad.

WRIGHT: At this moment?

SAM: Sad.

WRIGHT: More sad about it. And which one is easier for you to deal with? Which emotion do you feel more comfortable with? Is it easier to be sad about it or to be angry about it?

SAM: Angry.

WRIGHT: Easier to be angry. The sadness is harder? Can you tell me about that?

SAM: Well, it's just letting off steam, it's easier than feeling bad about it.

WRIGHT (*looking at Henry and Dorothy*): Do you agree with that, do you think it's easier? Do you notice that it's easier for him to be angry than to be sad?

DOROTHY/HENRY: Yeah, oh yeah.

WRIGHT: That's a harder emotion. What about for you, what's the harder one for you to see your son experiencing, sadness or . . .

HENRY: Sadness.

WRIGHT: . . . or anger? Sadness.

HENRY: I'm glad when he's angry and shouts and screams and lets it out, then he's good for a while. But when he's sad and sits there and we ask, "What's the matter, Sam?" and he says, "Nothing," . . .

DOROTHY: . . . doesn't say anything, just sits . . .

HENRY: . . . no conversation, just watches TV . . .

WRIGHT: Actually, in some ways it probably takes more strength to be sad, doesn't it, than to be angry. Because, like you say, when you're angry, it's over . . .

DOROTHY: Oh yeah, it's over.

WRIGHT: But it takes a lot of strength to be sad. When you're sad, do you cry on the inside or do you cry on the outside, Sam?

SAM (*very softly*): Both, I guess.

DOROTHY: Sometimes he cries.

HENRY: Oh yeah, he has incidents of crying.

WRIGHT: Because I've had other patients with MS and other illnesses tell me that crying on the inside takes more energy. They find when they cry on the outside and let the tears come, that it doesn't take as much energy. Do you find that?

SAM: Yeah.

WRIGHT: It's harder, and it seems like it saps your energy more if you just cry on the inside, eh? So sometimes you allow yourself to cry on the outside?

SAM: Yes.

WRIGHT: Good. That's good, eh? Do you understand what I mean?

DOROTHY/HENRY: Oh yeah. I wish he would do it that way all the time.

WRIGHT: That he cries on the outside.

HENRY: Have a darn good cry and then . . .

WRIGHT: . . . just like anger then, it's out, doesn't take as much energy. But being sad all the time on the inside, you're always being angry on the inside.

HENRY: It's eating away . . .

WRIGHT: It saps your energy, doesn't it?

HENRY: Oh yes, it's hard, yep.

WRIGHT: Do you ever hold back or cry on the inside because you're afraid it might upset your mom and dad? (*Pauses.*) Would you ever hold it back because you're . . .

HENRY: I hope he doesn't. I wish, if he wants to cry, let him cry.

SAM: I don't think I purposely do.

This heart-to-heart conversation about Sam's experience of his illness was, ironically, a trigger for a heart-to-heart conversation between my parents. As I was doing the final revisions of this chapter, I happened to be visiting my parents. I asked whether they would be interested in reading it, particularly since the first part is largely about them. They eagerly responded that they would. Afterward, my mother put down the chapter, looked straight at my father, and asked, in a very soft and inquisitive tone, "How do you think my MS has affected our marriage?" My father responded, "I think it has brought us closer." Then my father asked my mother, "How do you think it has affected us?" My mother responded with her worries: "I worry about what the future holds for us; how bad am I going to get?"

I sat in silence and was mesmerized by this brief but poignant conversation between my parents. I was taken aback that they had no need to comment on my chapter or to talk with me but rather immediately began speaking with one another. This chapter created an opening for them to talk, for even a few moments, about their illness experience. How much more quickly a competent and caring health professional could have brought their suffering forth and facilitated a conversation. I was very

much the daughter as I listened to my parents; I could not speak or intervene, and had no need to. But later I wished that this conversation had happened much earlier and was angry and saddened that they, and I, had been offered no such opportunity.

As I was completing the chapter, another serendipitous experience happened. Dorothy called the Family Nursing Unit requesting to be seen again. I was surprised to hear from her again after six years. As I greeted Dorothy in the waiting room, I thought she looked only a little older but much less strained than before. During our session, she informed me that her beloved Henry had died some six months before from ALS disease.

Two years before, Sam had entered an extended care facility, permanently disabled with no functioning in any of his limbs. He had to be fed by a tube and was completely dependent on health professionals for all his physical care. When I asked her whether Sam was suffering, she said no. I was quite amazed at this answer after her description of his condition. She added, "He's adjusted to his condition. He's been through so much and is such a fighter." Sam had healed emotionally.

In my own family, we have coined the term "trooper" for my mother, who has worked so hard to do what she can for herself. Her remarkably positive spirits have been an inspiration to us all. During the weepy times she has, my father has lamented that her tears have been the most difficult aspect of her illness for him. Perhaps my mother works hard at being a trooper and not weeping so that my father will not feel helpless. It is my hope that my mother has also emotionally healed.

Dorothy informed me that she was advised by a health professional to go to a "grief group." She went to the group and discovered that she was "grieving just fine. I came home and decided it wasn't grief that was my problem, but fear." When I explored her fears, she told me she was fearful of Sam dying: "He's all I've got." And she was equally afraid that she would die and leave Sam with no family in the city. She was also planning her first short trip without her husband and worried that Sam might need her while she was away. She stated that Sam had told her he would be mad at her if she didn't go.

In our reflecting team, we commended this wonderful woman for her many years taking care of so many people in her life: her father, her father-in-law, a friend, her husband, and her son. Her whole life had been devoted to caring for others during their experiences of illness. Our reflecting team also offered her ideas for what she could do to be more comfortable about taking a trip: buy a cellular phone; call home at a regular time each day when away to have contact with Sam. We also validated that we thought she was grieving as she needed to and that some things only a mother can do for a son, no matter what the ages.

Dorothy was very touched by our comments and stated that she felt better at the end of our session. She also requested one more session. I look forward to seeing her again to be a witness and confidant and to trying to facilitate healing for her illness suffering. I'm confident that my

clinical team can alleviate Dorothy's suffering, just as I'm confident that I will continue to learn from her.

What I have learned over the past 20 years working with families experiencing illness is that my primary goal in the therapeutic process is to create an environment for alleviating and/or healing emotional and physical suffering from illness. One beginning way to alleviate suffering is to acknowledge that suffering exists. In so doing, we recognize the patient and his or her family as the suffering others. And by witnessing their illness narrative, we also come to recognize the patient and family members as the heroic others, the giving others, the receiving others, and the compassionate others.

I asked Sam in my first meeting with him: "What's the toughest part about managing MS every day and coping with it?" This therapeutic conversation was not about symptoms, or medication, or treatment, but rather about this young man's illness experience; the specific intention was to understand the potential or actual areas of suffering. He gave a poignant response about his beliefs: "Things that seemed so trivial I can't really do anymore. They're not really important things, but everyone does them."

Sam helped me to learn and remember that many of the daily tasks and routines that are normally out of our awareness and taken for granted are gone *out* of his capabilities and *into* his awareness in the context of illness. I was reminded of my own experience in assisting my mother with bathing and eating. Turning on the water taps, doing up your own brassiere, and spreading jam on your toast are just a few of the things that, as Sam taught me, "are not really important things, but everybody does them." That is, everybody but Sam, my mother, and countless others for whom these tasks and routines accentuate their dependence on and difference from others.

The privilege of working with families invites me as a clinician to reflect on my own beliefs about illness experiences. Of course, there are no correct beliefs for families to possess when coping with illness, only beliefs that are more freeing, useful, and facilitative for the lives and relationships of family members. I acknowledge the contribution of the beliefs and stories of families experiencing illness to challenge or affirm the illness beliefs in my own life and relationships as I witness the healing in others. This is truly one of the gifts of working with families experiencing illness.

I know that family healthcare exists in some health settings, but I still meet far too many families like my own who have to be detectives and sniff out information about the disease and figure out alone ways to cope with the awful attack on their lives. And in the process, emotional and physical suffering goes unattended because the illness experience is not brought to the fore and discussed. Healthcare of ill individuals does fall on the backs of families, but it is far from routine practice for health professionals to include and assist families. Let us hope that by telling our

personal and professional stories of illness more often we can inspire much more collaboration, caring, and healing between health professionals and families.

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