Introduction

Coming to a research symposium on the health issues of women with physical disabilities, as a non-researcher, was a real challenge for me. I pondered what my role might be, since I wasn't immersed in studying, collecting and analyzing data, posing theoretic questions and all the other things that I think "researchers" do. I thought I'd do an informal survey of rural women with disabilities, but time got away from me with a busy work schedule, death of a brother, and a range of other stressful events that inevitably follow me around as I pursue those activities of daily living. In the end I realized, all I had to give was my personal perceptions as a women with a physical disability on a topic that may be too hard for research to try to tackle. That topic is on giving.

It is probably stress and depression that are the driving forces urging me to face what I have been evading for years. The combination of a brother's death, a look again (in reading and preparing for this symposium) at all the things I should be doing, the growing agony of staying upright a little longer, all these factors have guided me into this inward journey to look at life and health in a new perspective. I recall from my graduate school days, that facing depression and the causes that took us there, is a healthy, growth experience. I needed to see what I was hanging onto, recognize what had disappointed me, faced what I was afraid of, and "giving" was at the core of it all.

The word "giving" is one of the most open, flowing, generous, bountiful words in the English language. We are all exhorted to give and give even more. So it disturbed me when I realized how the word "give" is worked into a lot of negative implications like "giving out", "giving in" and "giving up". I am challenged to see these words in some positive way. I have to; -- I am giving out in my body, giving in to my weaknesses, and giving up dozens of activities and images that have defined me for years. How to find the goodness in all of that giving?
Giving Out

Living with a progressive (damn it - there's another positive term!) disease like muscular dystrophy, I know that change in ability, limitations, pain etc., is inevitable. I never had thought of myself as severely disabled because I still transfer from my scooter to a high desk chair at work. At home, in the evenings, it's a lazy man's recliner that tilts back and lifts me up and forward so that I can still get up and stand on my own. I still walk, using a walker in the house for short (inaccessible) places. I do my own toileting, face washing and putting on moisturizers and lotions. I do a lot of those "activities of daily living" on my own. But every movement given up, as body gives out, is noticed. One by one, day by day, less for me to do, more for my husband to do.

My back is giving out and with that my balance. My legs are giving out, and with that my endurance to stand - at the sink in the morning. My arms and shoulders are folding in like broken wings awkward and impossible to sleep on at night. Only my hands are strong and able. My neck giving out has rendered me into a whole new status of humility. Actually the effect of weak neck muscles is a strange dance between a look of haughtiness with my head thrown back when I am riding in my scooter, to a humbled look of head bowed downward when I am walking. It doesn't help that the walk from recliner to bathroom to bedroom at night has gotten to be excruciatingly long and slow. I wonder how long I will be able to continue. And I wonder how different things would be if I were a few dozen pounds lighter, and I exercised regularly. It's a guilt trip for sure. But it's also muscular dystrophy and I've never been able to get anyone to give me a definitive answer on how the two mix.

There was a time when I was lighter - most of my life really, and I did exercise for years. From Jack LaLanne on TV, to a Jane Fonda Workout at work to Slender You Fitness Centers, to exercise bikes at home, to serious disco dancing on the weekends - I was younger, lighter, able and attractive. That was then, this is now: I'm older, heavy, disabled and subject to the little discriminations inherent in being all three.

I admit it, I live a sedentary lifestyle. I watch TV in the evenings in my recliner. I don't exercise - although I always believed that "still standing" was in itself some kind of feat. And at age 58, I still work full time and travel at least a dozen times during the course of the year. I have achieved a long time goal of writing and publishing a book about my mother, and in the summer, when the pool water exceeds 77 degrees, I do get in and splash and kick up a storm.

Research Implications for Giving Out

I don't believe that I am a rare case in my giving out experiences. There are thousands of women with MD, MS, Post-Polio, Chronic Fatigue, and maybe others who are just feeling the effects of growing older with disability -- that are giving out in body. What exercises, if any should we be doing? Can one regime fit all the wide range of different situations we find ourselves in? Can we admit that maybe "exercise" is beyond some of us, and hope that we will not be forgotten or discounted in the greater world of health and research? Why aren't we encouraged to do more of the things we do have control over - like our diets, our breathing, or non-aerobic alternatives to relieving stress - like meditation, or singing, or art or? Our giving out is the beginning of our giving in and giving up - if this statement is true, what interventions can we take to make this process one that is not full of hopelessness and guilt and regret?
Giving In

To me, the "giving in" is the mental part of the process. As we are giving out, we are prone to give in to our weaknesses. It is a journey we take alone. Even those closest to us, who know our every movement, cannot join us in this place of what seems like overwhelming loss. As we give out physically, on a mental level, we are gradually losing our "participant status" and more and more taking on the role of "observer" in life. I depend on other things and people to be my hands and feet. I don't run into the convenience store when we stop for gas, I sit in the van and observe the physical activity of others around me. I watch them as they thoughtlessly move across the pavement - strolling, jogging, walking -- oblivious of the gifts they been given. I was there - like them in spike heels, or clogs, or slides, up steps, effortlessly participating in those activities of daily living.

Now I find the gratitude -- as legs turn to stone, and toenails curl and thicken. I wish I could live in a disabled world, but I don't. During those few times of the year, at conferences like this one, when disability is the norm - I feel at ease and blended in. For the most part, I live in a world that sees me differently. Whether in the grocery store or the mall, I see the quick glance; feel a certain amount of curiosity, fear or avoidance. I try not to let it soak into my skin, which has naturally grown thin through the course of this journey. Even in my family, I am architecturally excluded from most homes. And in my own home, I listen to the remarks of an over-worked husband who seems to be complaining endlessly about his lot in life taking care of me. It might all be in the guise of joking -- but I take it personally. "I am a burden", I berate myself. "Why can't I do more"? "Am I just being lazy"? "Why didn't I have the forethought or the courtesy to ask him to do something for me - before he sat back down?" "Am I really the self-centered thoughtless bitch, he makes me feel like I am?" Have we settled into some kind of destructive game playing to help us through what neither one of us wants to see?

I'm giving in to the idea that not everyone is going to like me, and that I am not like everyone else. I'm giving in to the truth that I am not perfect, but that I will always strive to be - despite appearances. I am giving in to the fact that despite all the focus on the physical, I'm not going to take it so personally. I want to give in to the idea and person I am today and quit clinging to yesterday's me and fretting about tomorrow. I might need to redefine who I am, as I have mixed up a lot of other images of who I was, am, and will be. I want to comfort this new me on my journey, be aware and supportive - not lay guilt trips and anger. I'm giving in, to myself and who I am.

Research Implications for Giving In

Must we take this journey alone? What is the research on using depression to break through to new perceptions about one's self and life? I can think of many friends who apparently did not survive the journey and who died young, sometimes at their own hand (men in particular). What are the effects of depression on women who are more isolated (i.e. rural women)? What are the effects of interventions like support groups or peer counseling with older women going through increasing limitation?
Giving Up

The visual image I have of giving up is hands extended upward to the sky in a fashion of surrender or acceptance. There are many things I have surrendered, including my driver’s license. There are some things I have been hard in coming to accept, like being a person with a disability. I believe this is a more difficult achievement for women who have been experiencing their symptoms a few at a time over the course of a long period. Contrary to the idea that we’ve had plenty of time to adjust, we never stop adjusting.

Though I realize I must speak for myself, I think the tendency is to cling to the able-bodied ness for as long as we can. I gave in to using a cane so I wouldn’t look drunk when I walked. I gave up my cane for a walker and gave up my walker (almost) for my scooter. Even my scooter looks less-disabled to me than those big electric wheelchairs. I resist giving in to that, but I know I must at some point -- especially as my upper torso weakens and I slump when not attentive to my posture. Why the clinging, the fear of giving up?

Perhaps I am fearful of how far it will go. How much of the spectator do I see myself becoming?

How will total dependency feel? Will the hint of panic that sometimes grips me in the night grow stronger? Will my legs freeze up completely? My older brother, who also has MD and has been a recluse for years likes to describe our condition as a struggle against gravity - and gravity slows wins out till it pulls us back to the earth. How long do I struggle against it? How can I say with confidence “This is it?” Will it take a few falls before I give up the walker? Do I hold out till the house is totally accessible? Will the physical therapist at the MDA Clinic at Ohio State University have something concrete to say to me, or do for me? I think I will give up hoping for that answer outside of myself. I am continually disappointed by the medical professionals.

When do I give up the struggle - or do I die trying?

Research Implications for Giving Up

How can surrender be used in a positive way? Do women with progressive physical disabilities go through a long term grieving process? If so what are the outcomes? What indicators predict a positive outcome? What indicators predict a negative outcome? What interventions exist that address the grieving process and does it apply in this situation?

Giving Back (written three months later ...)

The writing of the above paragraphs was the start of a journey I didn't know I needed to take. As I began the writing project, I thought I was being clever, couching a lot of negativity into what I perceived as a cute package. I thought that the cunning approach would numb me to the heat that was rising with the realization of how low I had allowed myself to get. This paper and the symposium, followed by a visit with my family (especially my brother who also has MD) opened my eyes and my mind to the real crisis I was facing.
I hadn't realized how depressed I was. When I thought about all of the loss I'd endured, I had probably been sinking into deeper depression for two or three years. It came on as insidiously as the muscular dystrophy and as unnoticed as the pounds that accumulated on my body. As stress piled up and my defenses were weakened, it created a cycle of lower energy, greater vulnerability, insomnia, unconscious eating, weight gain, and lowered self-esteem. What is scary is that I was able to function so well in my work world and mask the majority of my distress. (Or so I think, there were moments of inappropriate breakdowns, not to mention the bloated body I presented to the world)

In hindsight, I can see how the combination of MD, depression and weight gain almost succeeded in casting a mystical spell over me. It was as if a whole other person was assigned to the spot I once occupied. Heavy, restricted, dependent and insecure, I let a flood of outer influences overwhelm me - one after the other - and I was powerless to fight back. Coping was more than I could achieve. Thriving was out of the question.

Coming back home after my Houston trip, I was on fire with anger. My brother was much more independent than I. And even though I live a different lifestyle than he, I knew my weight was a big factor in my growing limitations. I envisioned a twenty pound bag of dog food (the size we buy to feed our yellow lab). How about two twenty-pound bags - one tied on the front and one on the back of my torso. That's the extra weight I carried around with me every day - at the very minimum. I certainly didn't need that on top of a progressive muscle disease. What made me even angrier was when I realized the one thing I had control over - what I put into my mouth - I had thoughtlessly abused for the past several years. In fact, I exercised no control. And now I was faced with the effects of all that mindless eating.

Once I realized where my past choices had gotten me, I immediately resolved to take charge in this area of my life. I have rarely faltered on this new course. I eat what I should be eating - every day. After years of reading about what's good for me, there were no excuses. I knew. And I can honestly say, I don't feel deprived, or even hungry. At the MDA Clinic I was told that I ought to count calories too - keep the count under one thousand per day if I really wanted to lose pounds - especially with my sedentary lifestyle. Any exercising I do would just help the cause. It may take as many years to take off the pounds as it took to put them on - I don't care. I want to be in control.

Another area that I have control over is my thinking, speaking and listening. No more blaming or feeling guilty, or digging up excuses. No more tolerating other's derogative remarks - no matter how they may be presented. I am looking out for my own well-being and I know what weakens me. I am slowly reclaiming a sense of empowerment that I had earned after years of hard work. I deserve to get what I want. I am able to control much in my life that is healthy and good for me. Here's a list of what I can do NOW...more could be added for sure:

- Put only healthy foods and beverages into my body
- Take a dip in the pool at least three times a week (summer's almost over)
- Movement - no matter what, when or where
- Breathing exercises - five times a week, twice a day
- Relaxation - especially as I prepare to sleep
- Practice seeing the beauty - in nature, my home, myself and others
• Practice an attitude of gratitude - give thanks for the many gifts I have
• Nourish the Soul in ways that are meaningful to me
• Be kind to everyone and everything
• Love much
• Stay clam
• Sing
• Write in my journal.

In the final analysis, the Giving back is a process of reclaiming that feeling of being empowered - in the face of continuing loss. I cannot give nourishment to others, if I am starving myself. Empowerment is something that transcends physical, mental and emotional challenges. It is living from that place where no disease exists, no damages can occur, no pain can penetrate. To me being empowered means having the grace to overcome. It is the ability and willingness to take control of those things we can control, willingness to accept those things we cannot control, and (as St Francis Prayer extols us to) have the wisdom to know the difference between the two.