

## Overcoming the Tyranny of Space: Experiences of Multiple Sclerosis Patients

*Narratives of MS patients, obtained through authors' research on their activity space, have revealed innovative ways in which patients overcome spatial constraints. These narratives reveal MS patients not merely as passive sufferers but as people actively engaged in enabling, even ennobling, themselves to have varied and positive experiences toward leading a meaningful life. MS patients' ability to overcome many spatial barriers has, in fact, been an important factor in reevaluating the authors' own views about disability experiences.*

by  
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*"Space is a tyrant and distances enforce his rule. He militates against us, often disposing of what we propose if our plans ignore his influence. The revolution against him is already well begun, however. Among the most disloyal subjects are geographers and regional scientists."*

*William Warntz (Presidential Address for Regional Science Association 1967, p.7)*

**W**arntz's statement holds very true for (MS)Multiple Sclerosis patients, for whom space is indeed a tyrant, posing a major barrier in performing their daily life activities. Most activities of daily living are generally performed in assigned spaces. In a capitalistic and modern society, the home space is very distinct and separate from spaces assigned for work, education, shopping, banking and recreation. To be able to perform activities successfully at these nodes, one needs the ability to overcome spatial distances and obstacles. When disability in the form of MS strikes, it severely restricts mobility and impacts directly on this ability to negotiate space. It becomes very dif-

ficult, sometimes impossible, to perform work-related and routine activities of daily living. Despite these constraints, many people with MS are able to overcome the spatial barriers and obstacles. How they are able to transcend spatial constraints is the underlying theme of our research and these narratives.

### About MS

MS is an unpredictable chronic disease that frequently results in several disabilities such as restricted motor abilities, coordination, vision, strength, speech, bladder control, and other faculties governed by eyes, brain, and spinal cord, which greatly curtail the mobility of individuals (Lechtenberg, 1995). It strikes individuals in the prime of their life, between the ages of 20 to 40 years, thus devastating many a life's plans and paths. Though the disease remains a mystery in terms of its cause and cure, some facts have been established. It strikes people of white races and more women than men in the ratio of 2:1 (Lynch & Rose 1996).

### Context

Our study was part of a larger study on the activity



space of MS patients in the Akron (PMSA) and Canton-Massillon (MSA) areas of Northeast Ohio, this being one of the high-risk areas for MS in the United States. In-depth interviews were conducted with 53 MS patients between the ages of 20 and 55 years. We selected from our research narratives of only female MS patients to illustrate how they incessantly try to overcome the "tyranny of space" (a phrase coined by William Warntz, 1967); that is, they try continually to engage in routine daily activities to maintain, even enhance, the quality of their lives. Often the invisibility of the disease and its symptoms becomes a cause of misunderstanding between the patient and the family, the caregivers, and the society, leading to increased stress for the MS patients.

### Narratives of Overcoming Spatial Constraints

In performing their daily activities, the MS patients, conscious of their spatial and social limitations, give much thought to planning. This is illustrated in the narrative based on an interview with a 49-year-old Registered Nurse, who has stopped working due to her MS and related stressful job conditions. Though she has no outward signs of the illness, she is suffering intensely:

*"The thing is that if I'm gonna go upstairs, I'll get everything upstairs done that I want to get done, until I have to go back up to bed at night. And if there's anything down in the basement, I get it all done when I am down there*

*the first time. I don't want to go back down unless I have to. Like right now I am doing a wash downstairs. Now I pace myself as to how frequently I am going to go up and down the steps. And while I was down there, I cleaned up the cat litter boxes, because they needed to be done, so instead of making another trip down there, I just, you know, you stand in the middle of the floor and look around and say, OK what needs to be done here, get it done now, and the same way upstairs, you stand in the middle of the floor upstairs, in the hallway and you look around and say, OK the beds are made, the clothes are put away, you know, it's dusted up and swept, the bathrooms are clean, OK let's take my bath, let's get me cleaned up, and then the last trip up here will be for bed at night, and that's what it is. If there's things that I need during the day, if someone's here, I send them up to get it for me, if not, then I wait or do without. It's called conserving energy. You know, it's a weird disease. You know, you are very limited in what you can do. You really have to plan how to do things. You know, like if I know we have a Christmas party Saturday, I would do nothing Saturday, nothing, so that I have all my energy to be able to get ready. To get ready, I know it's going to take everything out of me, so I may get ready for this party two hours in advance, so that I am able to get myself dressed and sit down here on the couch, long enough to get my strength back up and again to get out to the car, to go to the party. You just have to do a lot of planning, you know, for somebody that has MS, to be able to get around."*

The narrative illustrates how she negotiates home space

and how those with MS need to plan for every activity they perform to save energy, reduce fatigue, and increase efficiency. Unfortunately, the spontaneity of performing certain tasks is taken away; each task becomes an immense project. This individual, however, uses meticulous planning, given her limitations, to perform household tasks that are spatially proximate.

The narrative also highlights the layout problems of a two-story home with a basement and two flights of stairs. Such a fragmentation of living space with upstairs bedrooms, laundry in the basement, and living room and kitchen on the first floor hinders accessibility and leads to dependency on others for small tasks like carrying laundry or fetching something from upstairs. By bundling activities together and by planning, the MS patient tries to overcome the architectural constraints of such a dwelling place. Through effective activity planning, even in a poorly designed dwelling, this innovative nurse with MS has been able to maintain a sense of independence, so highly valued in our society.

The second part of the narrative depicts how an exciting socio-religious occasion, a Christmas party, could become a great burden for someone with MS. But instead of withdrawing from her social commitments, this individual has developed a well-planned strategy to conserve her energies so that she can drive to the party and thus continue to stay socially engaged. She overcomes the tyr-



anny of space through personal planning.

The next narrative from an interview with a 40-year-old female, earlier a Realtor and now a receptionist/secretary, is an example of a spatially "non-fungible" job activity, which the person substitutes with a different and more suitable career adjustment. Spatially non-fungible activities are those whose location cannot be changed without significant loss of their integrity. A change of location results in the loss of participation in that particular activity:

*"That was the biggest thing. That was my biggest adjustment, was my employment. I tried, I hadn't felt good as a realtor, sold houses. And for the last two years, I was on that job and I felt I couldn't do it, and I was really struggling, and my income went down, and I needed to find a different job so that I could have an easier time at work. Really, I got to say, this became my biggest adjustment, because the heat you know, affects you and I would be holding an open house, and they wouldn't have air conditioning, and I would get hot and then I would have trouble walking and plus you have to carry a lot of stuff when you are showing houses, you wouldn't think so, but you do, a lot of paperwork, briefcases, and that got to be difficult. And I needed to find a desk job, something that was not physical. So now I have an office job, and the air conditioning, not real physical and a steadier pay too, cause when I was selling real estate, that's real. It fluctuates, you don't know you are going to have money coming in or not, it was very unpredictable, and I said, my disease is unpredictable.*

*I don't need everything in my life to be unpredictable, I wanted something that was steady and I knew I could count on it, you know.....I was a realtor for eight years; it was a big change. After finding out that I had a disease that was incurable and unpredictable, I tried to hang in there for a year, I worked a year after being diagnosed and I just couldn't do it, too difficult. It's very stressful, too, to sell houses, buyers and sellers, you know, arguing and getting mad at each other and I in the middle, you know. I just didn't like that."*

This MS patient illustrates how, with increasing problems with MS, she changed her career path in order to continue being employed. She accepted the reality of her disability, but did not become disabled. She opted for a job that better suited her needs, a job that would be less physically demanding yet offered job security and provided a steady income. A realtor's job is not only spatially non-fungible but also spatially spread out. The receptionist/secretary job, though also spatially non-fungible, is confined to one location and is much less physically demanding. Thus, through substitution of a new career path, this woman with MS overcame spatial and economic uncertainties.

Next we hear from a 51-year-old divorced female employed as a program coordinator in social work, a very demanding job that requires much more than regular hours of work and also some traveling. While she meets her professional obligations, she is unable to devote the same energy on the social

front:

*"I don't visit as frequently as I used to. It's not that I do not keep in touch with friends, because I do. But a lot of us with MS are like compulsive people. I go in for work, as long as I do my 40 hours a week, I usually end up doing 50 or more a week, there's just so much that needs to be done. I am usually so tired that my weekends are so pressured. It's my time to withdraw and be refreshed. It's more that I talk to them on the phone than visit. I do have a problem with a lot of steps in a house, leading to their houses. I'd rather have them come to my house."*

This MS patient expresses a need for spatial role reversibility and for spatial negotiation of social roles. She desires that friends visit her. In this situation the activity will be performed, but the location of the activity will shift to her home, allowing her to overcome spatial constraints and barriers, such as traveling distance and negotiating steps at the doors. This decision will help her conserve energy and simultaneously better fulfill her social needs, obligations, and relationships.

In the following narrative, a 51-year-old female, now a homemaker, describes how a home visit by a health professional can save an enormous amount of anxiety, hardship, and money when a person suffers from exacerbating episodes or attacks of MS. The spatially fungible aspect of medical services is well illustrated through this brief narrative. The shifting of some medical services to the home can be very helpful, save a lot of hardship, and im-



prove access to health care delivery. Fungibility of services related to food and medicine is recognized by MS patients but needs to be realized more by the providers:

*"This time when I had an exacerbation in August, I called up my doctor and told him that I do not want to go to the hospital. It's so expensive and so unnecessary as far as I am concerned. So the doctor set up a visiting nurse to come here. I have a tremendous rapport with him. It was a Saturday afternoon, and by 5:30 p.m. that evening I had the IV going."*

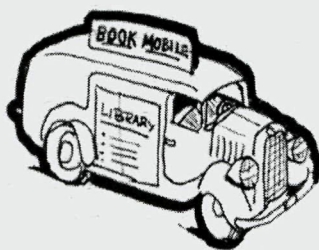
All the above individuals suffer greatly from MS, and though they have no visible signs of MS, their spatial access has been deeply affected. The invisibility of the disease means additional stress for MS patients since the intensity of their physical limitations, suffering, and pain is not evident from their appearance. This often leaves them with the feeling that there is a lack of understanding of their problems by the able-bodied. All of them drive, three are married, and all of them live in personal houses.

The next brief narrative is that of an intellectually inclined 44-year-old female and retired medical social worker. She lives independently in housing for the elderly. She uses a wheelchair but does drive a handicapped-equipped vehicle:

*"But the library book mobile comes here twice a month so I can request them to bring videos from the library. The library downtown is kind of hard to get into considering the parking, and you have to go down in the main floor which is in the basement,*

*the wheelchair ramp is long and kind of steep so I use the book mobile from here. That is one form of recreation, I guess."*

The library mobile service has great significance for someone who is well read, informed, and highly educated. The library book mobile saves her from enormous hardships of negotiating the barriers posed by the library building located in the crowded downtown since



it is an older building with a steep ramp. Thus, with this service, she fulfills her recreational needs together with intellectual needs. The library is an example of an activity which can have both the spatially non-fungible aspect in the form of the library building, which houses all the books and media, and the spatially fungible aspect in the form of the library book mobile which delivers all the requested articles. The second option, of course, does not allow one to explore the library's resources and is simply a convenient substitute. In this instance a public service helps an individual overcome the constraints of space.

The same individual provides another example of how

she uses a new technology — the Internet. At the same time, in the following narrative, she ponders the utilization of another kind of activity involving technology—Internet banking:

*"I have a support group on the Internet that I can e-mail through, and it happens to be for lesbians with multiple sclerosis so there's about 30 or 40 of us nationally and internationally that are in this support group. So all I have to do is put my chair right over there in front of the computer. I don't know how to do banking; I need to find out though. My problem is I am limited with my computer. It's a very old computer. I don't have a big server that a lot of people use. Since I can't do graphics or anything like that, just text, I can't use AOL. I think I'd be limited in doing things like banking. I don't think I'll be able to do that. I suppose it can be done, but I am kind of leery about doing banking over the computer."*

This narrative provides an excellent example of utilization of a new technology, the Internet and e-mail, for support, social and recreation purposes, a technology that clearly helps overcome barriers of space, time, and distance to allow like-minded people to join together and form activity bundles in cyber space. This person may be fearful of social marginality in the real world, but finds the Internet an empowering technology.

On the other hand, this individual has concern about one aspect of the new technology. Internet banking is a spatially fungible activity allowing one to perform numerous,



though not all, aspects of banking from a personal computer. Even though the function is fungible, the person is not comfortable with the available technology to take advantage of it by substituting cyber space with metric space, for obvious well-known security concerns. But despite that, it does provide an option for one to avoid traveling to perform banking functions.

The final narrative, quite different from the above, is of a young student, single, female, 20 years old, who was diagnosed with MS three years ago. She lives with her family, who is finding it hard to learn to cope with the disease. She attends school at a nearby university and her narrative illustrates her mature approach to resolving her spatial problems:

*"Most of my activity is right here, mostly at school, because everything is right there. I can walk to anywhere. I would have liked to switch to another university, one that does not have other businesses. Most of the buildings, like social security, all the main government buildings are right downtown. So if I ever need to go there, I know I need to go to social security a couple of times of year, I can just walk a block and I am there. So that is all it takes. I don't have to try to find a ride. I know that the other is a better school but it is more convenient for me just to hop on a bus and go downtown. I walked down to main campus, and then I started getting sick and I don't know what was wrong with me. I realized that I would have to go down to the C and T college (Community and Technical College)*

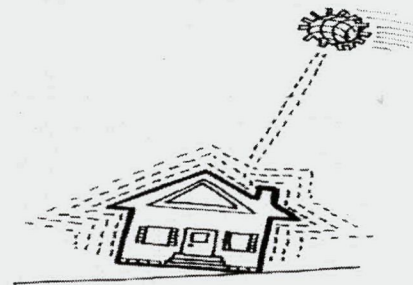
*which is a small college in a college. It's all in one building, because I'd have such a hard time walking so I went there. I think it's the best decision that I have made. I just signed there for business management and some accounting. I will work for an Associate in Accounting degree or Public Relations."*

She describes the reason for making a choice of attending her present university which she feels is more compact, better connected by public transit, and more conveniently located to her home and to other facilities as opposed to the other university. Her university is located in downtown, which is about 10 miles from the other. While she thinks that the other university has a better program, the more spread out campus and less accessibility by public transit pose major spatial barriers. Thus, by choosing the present university she overcomes the spatial barriers. Also within her university she decides to attend the Community and Technical College which, housed in one building resolves even more spatial barriers. Thus, she maps out her career path and her physical daily space, freeing them from as many spatial barriers as she can and at the same time overcoming the spatial non-fungibility of the university.

### Reflections

Persons with MS must make many decisions in their everyday life. They have to continually devise ways to overcome numerous social and spatial barriers and constraints. Sometimes they circumvent space altogether. One of the

ways is through the substitution of metric space with cyber space. For example, Internet banking can replace actual travel to the bank, or a visiting health professional may save a trip to a medical facility. Here a selective reversal of space negotiation takes place, in which instead of the individual with MS traveling to the facility, the provider travels, either in person or through cyber space. Thus, space is substituted either with a technological or a social transaction. The need by an MS person to travel to or be present at another location is obviated. Through this process, the home



space begins to take on a meaning different from that of simply domestic space.

From all the narratives, we learn that disability should not be tantamount to disengagement. More frequently than not, it means even more active interaction with the social and spatial dimensions of the world. Adaptation and innovative modifications, impelled by a drive to maintain individual dignity, lead MS patients to strive toward a full and meaningful life. As we have already noticed, one individual consciously changed her career path



from a realtor to a secretary in order to gain job security and to reduce spatial activity. The use of technology to overcome spatial barriers to social interaction is clearly demonstrated by the individual who uses the Internet to associate with lesbian support groups. Active and conscious planning decisions of the choice of school to arrange tasks to carry out routine household chores are all examples of conscious planning, decision making, and societal engagement.

Through this research we have become aware of the efforts of the MS patients to tame this tyrant and that more attention needs to be focussed on how individuals with MS are constantly in the process of taming space despite the constraints and barriers they encounter. Though space may continue to exact its costs, the positive striving of people with MS does need to be highlighted. As a result of our experience with MS patients, we have more clearly begun to recognize the limitations of conceptualizing human problems within one specific disciplinary framework. Whereas spatial (geographic) issues may be of critical importance from a disciplinary angle, social, psychological, and personal problems may be paramount from the MS patients' perspective. Therefore, interdisciplinary insights are necessary to address complex human issues such as disability. We have increasingly come to recognize that illness is a dimension of disability, but disability is not an illness. It has become necessary for us to reevaluate some of our attitudes about MS

research.

Instead of conceptualizing research in terms of limitations and barriers alone, we have begun to redirect ourselves toward innovations, substitutions, alternatives, and other positive coping strategies in which persons with disabilities are active participants. Our research has helped us to overcome a stereotypical image of disability as inability. In addition, patient narratives provide human insights that numbers alone cannot. Methodologically our future research will draw attention toward developing measures of ability.

These narratives inform the geographic concepts of activity bundles, paths, projects, stations, and constraints developed by Torsten Hagerstrand (1970, 1975) and other scholars (Pred, 1977). Although the fundamental idea of different types of constraints (capability, authority, and coupling) are valid, we need to bring out the participatory role of persons with MS in overcoming these constraints. Hagerstrand (1975, pp.10-11) feels that constraints can be imposed by society and interact against the will of the individual. First, the capability constraints are "imposed by physiological and physical needs and some imposed by private and common decisions." These limit the activities of an individual because of biological construction (the need to sleep, to eat, to rest, for personal care) and/or the tools one can command (own a car or the distance one can cover within a given time-span). Second, "The coupling

constraints refer to activities undertaken jointly, determining where and how long the individual has to join other individuals, tools and materials to form production, consumption, social and miscellaneous activity bundles. Examples are that student and teacher, customer and salesman form activity bundles." Third, authority constraints are when an individual's "set of potentially possible actions is severely restricted by the presence of other people and maze of cultural and legal rules." Time geography "focuses on the constraints which in both obvious and subtle ways limit the individual's freedom to move from station to station and choose activity bundles" (Pred, 1977, p. 638). Our focus has been on how MS patients overcome these constraints.

The significance of spatial constraints and barriers needs to be rethought. Patients may use their time and space differently and utilize the modifications as positive changes in their life, rather than as mere substitutes. By innovative thinking and adaptation, MS patients are able to circumvent space or chalk out alternative paths to perform their activities, thereby changing meanings assigned to different spatial locations. There is a need to redefine the meaning of home-based and spatially segregated activities. The boundaries between these seem to be fluid and in a constant state of flux with the changing manifestations of disability and the adoption of enablers.

Our purpose is to show not how helpless, but how inno-

vative, a person with disability is. With more enabling technology and more active thought, the environment/space can be reshaped and reconfigured to suit particular individual needs. The person feels a degree of empowerment and not just helplessness. By focusing on the relative spatial fungibility of activities, we found that MS patients are actively engaged in shaping and reshaping their worlds, just as, if not more vigorously than, "able bodied people" do. Acceptance of such perspectives should help reduce stigmatization of patients and project a more positive image of people with MS as capable of shaping their environments, rather than accepting the tyranny of space, metric or social.

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