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Multiple Sclerosis in its Context: Individual Narratives

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The meaning of a disease depends greatly on the context in which it is embedded. For multiple sclerosis (MS), significance of its context becomes critical because it is a chronic and unpredictable disease and the consequences of its disability manifest very differently in a variety of contexts. In some individuals one disability's consequence may be dominant, but in others several disabilities' consequences could occur together. In fact, it can be argued that MS is a cluster of interrelated disabilities. For example an individual may simultaneously present impairment of motor control, shaking of limbs, shaking of eyeballs, partial loss of eyesight, and even certain cognitive disorders and each one could lead to a disability. Thus the same "disease" behaves very differently in different contexts.

This situation is quite unlike the relative uniformity of symptoms of many other diseases, especially acute infectious diseases. Disabilities of MS arise partly from the endogenous effects of the disease, but also from the societal externalities in the context of which the person with MS lives. The significance of society's role in how it "goes on disabling people with impairment" is increasingly being realized (E-mail from Ann McCutcheon, February 15, 2001).

Here, we examine the narratives of two individuals with MS to illustrate how the meaning of their geographic activity space is dependent upon their context, including their MS condition and their broader social setting. Activity space here refers to sites frequently visited by the individual for work, shopping, health, recreation, and social relationships. The narratives of persons with the same disease show a remarkably different meaning of their activity space because of their different contexts.

This paper first examines some interdisciplinary literature related to context and disability. It then briefly describes the method of this study. Third, using selected narratives, we describe the context of two case studies of individuals with MS followed by a short discussion.

Context and Disability

The prevailing disability paradigm emphasizes context in which individuals fulfill their daily roles rather than the clinical aspects of disability itself (Haley et al. 1994). Interactions of persons within the context is a major tenet of the disablement framework. The ICIDH-2, the International Classification of Functioning and Disability (WHO 1999) which is undergoing revisions, conceives functioning and disability as a dynamic interaction between health conditions and contextual factors which include both personal and environmental factors. In the same vein the National Institute of Disability and Rehabilitation Research (NIDRR) Long Range Plan (1999) also encourages researchers to explore new ways of studying disability in context taking into account the physical, policy, social environments and the dynamic nature of disability over the lifespan and across environments.

Although the ICIDH-2 distinguishes between the terms context and environment, in earlier literature the terms have been used interchangeably. In this paper we adopt the WHO definitions (WHO 1999:21-22) that define contextual factors as the complete background of individual's life and living and include environmental and personal factors. Environmental factors are external to the individual and include physical, social and attitudinal dimensions such as home and work environments, formal and informal social structures, services, and laws of the society. Personal factors refer to individual characteristics such as age, gender, race and education.

Geography, rehabilitation and environmental psychology, though separate disciplines, share common goals of understanding the impact of disability and its management. Within geography the importance of studying disease, health and place in the context of the environment - social, cultural, behavioral, economic - has been long recognized (Kearns 1993; Mayer and Meade 1994). Renewed emphasis on the significance of context in human and medical geography has resulted from the impact of postmodernism, social theory and feminist perspectives. Kearns (1993) talks about a socio-ecological model of health that involves an interactive set of relationships between a population and their social, cultural, and physical environment. Dyck (1992; 1995a; 1995b) and Moss (1997) provide examples of contextualized understanding of disability.

Informed by the occupational therapy perspective, Dyck (1992b) examines the case of a Chinese immigrant woman with rheumatoid arthritis to show how the individual's current environment, interwoven with her cultural beliefs and values, shapes the daily management of her illness. In her later work on unemployed women with MS Dyck (1995) focuses on how home and neighborhood spaces are renegotiated with a disability. Using Gidden's structuration theory she describes how routine activities, carried out in spatial-temporal settings, reveal ways in which the "society and the individual recursively constitute each other" (1995:3). Likewise, Moss (1997), in her case studies of elderly women with rheumatoid arthritis, shows how older women with chronic illness negotiate their home environments, both physically and socially. In mapping these micro geographies both Dyck and Moss position their work in the context of gender, age, race, culture, and disability to understand everyday lives and health experiences.

Rehabilitation professionals are now recognizing the critical importance of context for clinical assessment and outcomes research. Haley et al. (1994) depict the importance of context in assessment of physical disablement using the example of the performance of self care and mobility tasks by children with severe functional delays in home and school settings. Dunn (1994) provides a useful Ecology of Human Performance framework for considering the effect of context. This framework provides a structure of context as a key variable for assessment and intervention planning based on the interaction of the person and environment interdependent relationship.

More recently, environmental psychologists (Clitheroe et al. 1998) focus on the behavior of individuals in responses to `prompts.' They are concerned with ways in which physical and social features of the environment influence people's transactions with their everyday surroundings. Their model is useful in conceptualizing disability and disease in this study as a prompt or trigger that interacts with a host of contextual factors which in turn determines the spatial outcomes (Figure 1). The narratives in this paper illustrate the context and the spatial outcomes as perceived and interpreted by the individuals.

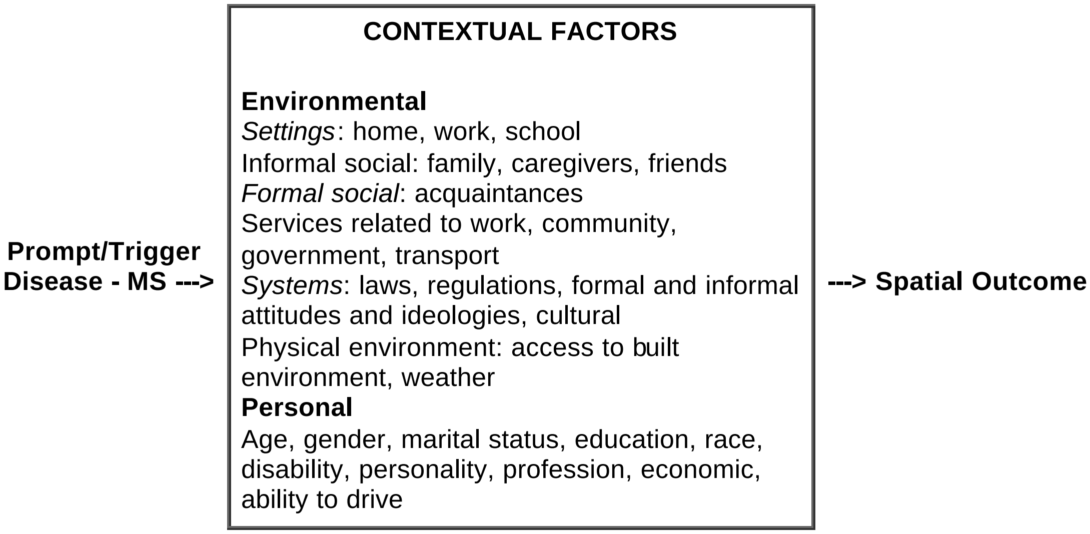

Figure 1.

Methods

This paper is part of a larger study on the activity space of persons with MS in Akron and Canton-Massillon metropolitan areas of Northeast Ohio, a high risk MS area (Thapar 1999). The two main cases reported in this paper are selected from a stratified random sample of 53 in-depth interviews that focused on issues on spatial negotiation, the nature of activity spaces and the impact of MS on activity spaces. With the consent of the participants the interviews were audio taped and transcribed verbatim. The interviews were carried out from November 1997 through March 1998. This long time period was primarily due to the fact that interviews had to be scheduled at the convenience of each participant. Most interviews lasted for well over two hours and some had to be rescheduled. Due to the amount of time required, and the specific needs of the participants for medication, diet, rest and comfort, interviews were generally carried out in the home environment including the two cases in this paper. The first two authors conducted several interviews together, including the ones reported in this article.

The following two selected case studies illustrate with narratives the context and varied spatial outcomes for two individuals living with MS. These selected narratives illustrate the significance of context in which a disease strikes. The spatial outcomes can not be attributed to disease alone, but to the entire context of a person which is a combination of a host of factors such as the social and economic conditions, support systems, age, gender, education, marital status and many more. Progression of the disease in both cases resulted in negative health outcomes and diminution of the activity space.

Case 1

Mr. C is a 55 year old, white, married, self-employed farmer. He was diagnosed with chronic progressive MS, the more severe type of MS, when he was 45. His disability level is now high[1] requiring 3 hours of daily personal care and making it necessary for him to use a battery-powered wheelchair for mobility. Earlier, Mr. C had led an active life as owner of a service station for 20 years, and later as a farmer, until he was struck with MS. Mr. C was a volunteer basketball coach and counselor at youth camps for 10 years. The progressive chronic nature of MS had a drastic impact on his life. He could not play his favorite sport of basketball nor could he effectively play a youth leadership role in coaching girls basketball as a volunteer.

I coached girls' basketball for ten years. You see the trophies up there. These things were taken away.

A recent incident triggered his decision to retire from farming where he was unable to help a cow as he helplessly watched the mother deliver her still-born calf.

I spot the cow, she's laying down having the calf.... And everybody else is gone and I see this cow is stretched out like she is dead or she has a problem. So this is what the MS that I have, I can live with it. I couldn't live with that. She [his wife] has a phone for me here. The phone wasn't here.... The phone book wasn't here (voice breaks). That particular day I have nothing. I can't get to the cow, I can't do nothing to the cow. I can't call for help. That's life or death. For me that's life coming down on the earth... I cried. I said, `Dear Lord, I can't help her.' But there was me with MS on that particular day. Because I had MS I couldn't help that calf live and that hurts, that hurt bad.

Deeply hurt by this incident, he is now transferring his farm to a young man who has been working in his employ. Although his wife drives him everywhere, and thus he has not reduced his activity space significantly related to shopping and leisure, Mr. C's major concern is with the perceived loss of his role through the loss of related activity, whether as girls basketball coach or as the male head of household. Since that activity helped define his role, the loss was substantial. Even in this loss, however, there is a sense of discovering the previously undervalued significance of his wife, his primary caregiver.

We got a van. She [his wife] put a hoist in it. My wife drives. That is sad. 19 years old, when I graduated from high school, I bought a service station.... For 20 years I was there. I worked on cars.... Now I can't drive a car. ...The first couple of years I drove it, but I can't drive now. She won't let me drive it and I do agree with her that it is dangerous for me to drive. I don't have the reflexes. I can't get my foot on the right pedal. It's not safe for me to drive.

My wife is the greatest. I have often wondered that if she had MS, would I be good to her as she is to me. I couldn't have reached the heavens and pulled a better lady. And, I am a good husband, but I could not be that good.

He is unable to visit friends as their homes are inaccessible, but instead they visit him. Thus his activity space has been transformed, but his social relationships have endured.

Friends don't have ramps for me to get up. They come here, and there's somebody here all the time.

Blows to pride can be as important as physical ability to access a facility in the shrinkage of activity space. Mr. C hesitates to participate in community activities because of a fall in a restaurant.

I was in a restaurant with my cane and I fell flat on my face. The friend of mine come over to help me, asked if everything was alright. I said, `Everything but my pride.' That was the last time that I was in a restaurant for a long time.

He participates in activities that he can perform in restricted space with limited abilities without embarrassment. He sometimes watches his grandchildren and helps a little with vacuuming, but does not do any other household chores. Outside of home he mentioned only three locations that he visited in the last year - a restaurant, ball game and the neurologist.

With the Americans with Disabilities Act (ADA) he has also considered changing his employment, but feels left out from its impact.

Disability act is everybody's fair for a job, but that has not included me. When the government did that, it cannot be a bad thing. I have not taken advantage of it. I have taken a seminar at Kent State University to find out what I am best suited for, but they don't know what I am suited for.

Though he does not dwell on the financial impact of MS but he mentions that he applied for Social Security and did not get it. He therefore had to sell some of his land. Being self employed he also has to buy his own medical coverage.

Although his activity space in geometric terms is small, intensity of spatial relationships at his home has greatly increased due to strong support from his wife, family, and friends. This is reflected in the way he shows his compassion, expresses gratefulness, and the degree of equanimity with which he copes with his progressively deteriorating physical condition. Underneath it all, the roles he has lost and the psychological impact of MS on restricting his activity space is evident. We wonder whether the role of space should be stressed as an active agent or as a mediator.

Case 2

Mr. P is a 38 year old, Native American who was diagnosed with remitting exacerbating (RE) MS at the age of 33. He has 11th grade education and 2 years of technical college, but would like to get some computer training to make a living. Currently unemployed, he is separated from his wife and 3 children. Having a moderate level of disability,2 he uses a cane for walking and sometimes a wheelchair. Climbing stairs is hard for him, and his general mobility has been severely curtailed because he can no longer drive. He lives alone in a rented apartment on the first floor. He depends on one friend and sometimes his sister for caregiving and mobility. He has Medicaid and Supplemental Social Security Disability (SSDI) Income. Unlike Mr C, he feels deserted by his wife. Unhappy by the plans his father and stepmother were making "to put me in a home because I needed skilled nursing [care]," he elicited his sister's help. She moved him from Tennessee to Ohio resulting, however, in a restricted activity space and limited social relationships. He maintains that due to MS disabilities he lost his job and his wife separated from him. Since he is only 38 years old, however, he is determined one day to go back to work, and maintains a positive attitude.

I wasn't going to stay put down in a wheelchair in a hospital for too long. The nurses thought I was most stubborn. I might fall, I might drag my legs, hold on with one arm, throw the other arm up on it and kind of push my body with it. I was bound and determined to get my legs going back in order, didn't want none of their help, for letting me try and do it.

At home he does his own cooking, cleaning and laundry. His sister helped him when he was in a wheelchair. He also helps his friend at the garage and babysitting. His friend in turn watches over his well-being.

I help out a friend. My friend tinkers with cars. I can't work on them myself but I help him figure out what's going on, and stuff like that, gives me something to do. I try to go over everyday.

If he doesn't see me everyday, he's over here beating on the door wondering what's happened. Few times I had him come over and pick me up, put me in wheelchair, and wheel me down the road. ...We treat each other like brothers. When he and his wife take off, I sit there with his two kids, I don't get to see my kids too often so I enjoy somebody else's kids, their dog.

Thus, Mr. P has developed a symbiotic relationship with his friend and this friend's family. Mr. P longs to reclaim some roles and relationships he has lost because he is separated from his wife and lives away from his children. The loss of relationships was not wholly his choice. It seemed partly to have been imposed upon him by the disease and partly by the actions of his close relatives. Thus there is some support for the view that society plays an active role in disabling individuals with impairments.

He does not like being away from home (Tennessee) and misses his children and social contacts.

I wished I could have stayed in Tennessee. If it wouldn't have been for my dad and my adopted mother going to put me in a home.

He has also encountered health insurance problems in Ohio.

Out of my pension I pay for part of my medication, all of a sudden Medicaid doesn't pay for them no more. They are starting to not pay for some prescriptions but they pay for other stuff. And I got so many allergic reactions, that the other stuff that they want you on, I can't take. And they don't look at none of that. They just look at what they wanna pay for what they don't wanna pay for. This state [Ohio] they are messing people on health care pretty good.

Also due to the unpredictably of MS he fears losing his independence.

That's one of the worst things. Being scared, wondering, like the doctor says, you don't know, when something's gonna... when your system goes bad, if its going to stay like that or if its gonna to go away. I've always done everything for myself and when I can't do for myself it bothers me a lot. I hope I don't get to the point where I'm in a bad shape. Even in a wheelchair, if my legs go, stay that way, I can suffice with that. If I can get stuff to, so that I can do my own cooking, and be able to do my own dishes, get in an out on my own, and getting one of those ... stick things, where I can get up into cupboard, where I can get something like a cup on my own, instead of asking for somebody or wait until somebody comes around and say, hey could you do this for me. I hate that.

MS has certainly restricted Mr. P's activity space, but his move to Ohio from Tennessee probably contributed to it as well, since he had to start developing a new social network. Whereas Mr. P's MS condition did contribute to his move, it was precipitated by his father's plans to place him in a nursing home. Thus context made a major impact on the outcome.

Although, there is a ramp to enter his apartment, there is little space inside for the wheelchair. Narrow doors hinder access to the bathroom and all other spaces while lack of grab bars prevents him from using many spaces efficiently. Outside the home he mainly visits the convenience store nearby and a few other stores. Twice a month he visits a doctor and counselor depending on a ride. He sees a neurologist 4-6 times a year and is undergoing chemotherapy. His banking can be done from home and a postal worker helps him with mailing needs. He daily visits his friend who lives nearby. He wishes to participate in recreation, support group meetings and outdoor activities but is dependent on other people for rides. The weather too restricts his activities.

The most I get out is when I go to the doctor, or when I go to the grocery store in a couple of weeks. I don't get out. I got stuck once here in the pharmacy. I made a mistake. I thought I could walk it. Trying to make it back, my legs just gave up. I had to sit there for a while. So I don't attempt to go too far.

He is considering other employment. As already stated, he has 11th grade education and 2 years of technical college, but would like to get some computer training to make a living.

There is one man in Alliance. He's got MS and he don't use his hands or legs whatsoever. And he's not on social security now. He makes a living from his home doing something on computers. His is completely voice controlled. I don't know exactly what. I figured if you can set me up with something like that, if he can do it, I can do it. Since then I haven't had anybody that would get me up to Canton right now. I can't set an appointment till I know I've got somebody that will take me. That makes it hard right now.

This narrative points out not only to the debilitation due to MS, but the contextual factors related to race, economic and emotional deprivation, and educational handicap that together result in a much reduced activity space. Mr. P.'s activity space is restricted to health related needs and a few nearby social activities. But it is not access to specific places that Mr. P. is really talking about. His concern is with the kind of future he is going to have. The critical factors leading to his restricted activity space are limited family support, inadequate finances and debilitation due to progression of MS. He also strongly implies that various societal components such as the intricacies of the Social Security system, lack of adequate local transportation system, and the actions of some of his own family members are together keeping him in a state of disability due to his MS impairments.

Discussion

Disease and disability are experienced by individuals in their highly personalized contexts. The spatial outcomes are determined by the interaction of MS with the individual's contextual factors - personal, family support, social, psychological, economic and environmental. The two narratives describe the unique context for each individual. In each of the two cases these form different combinations resulting in different social-spatial outcomes.

These two cases also show how contextual examination provides a greater understanding and can help target interventions at the critical factors. Because of the unpredictability of MS, individual context becomes all the more critical. The two cases describe the unique context for each individual's life. The activity space has shrunk in both cases, but not entirely due to MS. The meaning of that reduced activity space, however, is very different.

In the first case all the important relationships, especially of the immediate family and friends, have converged upon Mr. C's home. In the second case, Mr. P lives in a socially, spatially and spiritually fragmented world, trying to rebuild his life. In both cases there has been a loss of key personal roles. But in the second case the loss of several key roles and relationships is compounded by a sense of spatial and spiritual displacement. Mr. P. first `lost' his home and family, and is now lost in the new place (Ohio). He has, however, attempted to replace some lost relationships and roles through symbiotic interaction with the family of his only friend.

With family support, pension, and farmland to fall back upon, and without the need to worry for future employment, Mr. C. is able to maintain a relatively cheerful personal disposition even with mobility constraints due to MS. Manifestation of MS in the context of a caring family, and a successful earlier life experience of Mr. C., seemed to make the giving and receiving of care an acceptable experience. His physically reduced activity space was compensated to a great extent by family and friends willing to drive for him and to visit him in his home. His home became the center of his social activity space, though inability to participate in some activities (that could not be carried out at home) did weigh on his mind.

On the other hand, having been uprooted from his original home in Tennessee, having lost the very outdoor lifestyle of a Native American, and unable to access new technology for a possible job opportunity, Mr. P.'s life reflects uncertainty, even despair. The fact that he is only 38 years old is important in his context because potentially he has decades of productive life ahead of him.

In both cases there were references to distance as a barrier, but the meaning and significance of geographic space was expressed primarily in terms of the ability or inability to participate in social activities and social relations. Weather, mainly the impact of heat and humidity, is one aspect of the environment repeatedly mentioned by several persons with MS we interviewed. The personal outcomes of the MS patients are, however, determined by myriad of interaction with their contextual factors - personality, family support, social, psychological, economic, cultural and environmental. These two cases also suggest that contextual examination can provide greater understanding of the meaning of disease and activity space.

The two cases form different combinations of contextual factors resulting in different social-spatial outcomes. The changing nature of context and disability is well displayed by the case of Mr. C. He has made accommodations at his own level and through supportive care of his family. Successful careers and active community involvement through volunteering provided Mr. C with positive past experiences of a fulfilling activity space. At his age, he is not looking to a career for self-fulfillment.

Mr. P's quality of life, on the contrary, could have been much different if he had not been torn away from his family and from his preferred lifestyle in Tennessee. His activity space physically shrank, but more importantly became, for some time, deprived of fulfilling social and economic relationships, until he began to develop new strategies for social networks. These cases lead us to conclude that one cannot expect similar activity space outcome for different individuals simply because of the same disease such as Multiple Sclerosis because the meaning of the `same' disease is very different from one context to the other.

Conclusions

Our study highlights the significance of context in the activity space of two individuals with multiple sclerosis. Each individual's activities relate to a myriad of contextual factors. The personal factor of age, for example, makes learning new skills unimportant for one, but critical for the other. Family support makes a major difference in how the two persons experience their life: a nurturing, caring world for one; and a fragmented world for the other. In one case the house itself has become the nexus of many social activities. The other person has to seek substitutions for lost roles in a willing friend's household. In one case the home provides a secure psychological environment, in the other the very sense of home has been lost. In one, successful earlier career, and financial security can provide a secure retirement. In the other economic uncertainty looms large. The same disease has a widely different meaning in the lives of two individuals living in the same physical environment of Northeastern Ohio.

The significance that each case attaches to geographic space seems not to be as evident, however, as geographers might expect from their disciplinary perspective. Instead, what appeared more prominent was the meaning and significance they attached to activities and relationships with space as a taken for granted entity. The two cases that we examined illustrate major differences in outcome. The meaning of activity space as revealed by the two case studies seems not to be found in distances covered or space traversed due to limitations imposed by MS, but by participation in meaningful activities in space. For both persons activity space was not defined primarily by spatial parameters, but rather by the richness of the social-spatial content and its meaning in terms of human interaction. The meaning of physical space was most important at the immediate micro level in terms of negotiating barriers in one's house or apartment.

Notes

1. The level of disability was determined by using the Environmental Status Scale (ESS) by Fog and Mellerup (IFMSS 1985) that provides an assessment based on seven items of work, financial status, home, personal assistance, transportation, community services and social activities. The scale emphasizes performance rather than ability and highly correlates with disease severity.

2. See note 1.

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