The lived experience of disability*

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Abstract

In this paper I reflect upon my personal experience of chronic progressive multiple sclerosis in order to provide a phenomenological account of the human experience of disability. In particular, I argue that the phenomenological notion of lived body provides important insights into the profound disruptions of space and time that are an integral element of changed physical capacities such as loss of mobility. In addition, phenomenology discloses the emotional dimension of physical disorder. The lived body disruption engendered by loss of mobility includes a change in the character of surrounding space, an alteration in one's taken-for-granted awareness of (and interaction with) objects, the disruption of corporeal identity, a disturbance in one's relations with others, and a change in the character of temporal experience. The loss of upright posture is of particular significance since it not only concretely diminishes autonomy but affects the way one is treated by others. Such a change in posture is, therefore, particularly disruptive in the social world of everyday life. An understanding of the lived body disruption engendered by disability has important applications for the clinical context in devising effective therapies, as well as for the social arena in determining how best to resolve the various challenges posed by chronic disabling disorders.

My interest in the phenomenology of illness and disability has grown out of my own experience as a person living with multiple sclerosis—an incurable, progressively disabling disease of the central nervous system. Over the past twenty years (since the age of 30) my physical capacities have altered in a startling number of ways. At one time or another my illness has affected my ability to see, to feel to move, to hear, to stand up, to sit up, to walk, to control my bowels and my bladder, and to maintain my balance. Some abilities, such as sensing the position of a limb, I have lost abruptly and then slowly regained. Some, such as clear-sighted vision in one or the other eye, I have lost and regained numerous times. Other physical capacities has disappeared and never returned. I can, for example, no longer walk because I am quite unable to lift my legs. This latter change has, however, been gradual. For a number

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of years, although the muscles in my legs became weaker and weaker, I was able to get around “on my own two feet” using first a cane, then crutches, and finally a walker for support. Now I use a wheelchair or battery operated scooter for mobility.

All these physical changes can, of course, be described in terms of central nervous system dysfunction and explicated with respect to a demyelinating disorder. Indeed, it may even be possible, through the use of sophisticated medical technology, to visualize lesions in the brain to account for specific physical incapacities. Yet, such a mechanistic description (based as it is on a biomedical model of disease) captures little, if anything, of my actual experience of bodily disorder. I do not experience the lesion(s) in my brain: Indeed, for me and others with similar disorders, illness is not even experienced as a matter of abnormal reflexes. Rather, my illness is the impossibility of taking a walk around the block or of carrying a cup of coffee from the kitchen to the den.

In this essay I suggest that phenomenology provides a powerful means to illuminate the human experience of loss of mobility — a bodily dysfunction that is common in neurological and other degenerative diseases. In particular, in rendering explicit the dynamic relation between body and world, the phenomenological notion of lived body provides important insights into the disruption of space and time that are an integral element of physical disability. Furthermore, a phenomenological account of bodily disorder discloses the emotional dimension of physical dysfunction. In providing a window into lived experience, phenomenology gives invaluable information about the everyday world of those who live with disabilities. Such information is of enormous practical significance when devising effective therapies in the clinical setting and in determining how best to address the personal, social and emotional challenges posed by chronic disabling diseases.

In considering the meaning of disability it is helpful to recall the phenomenological notion of lived body (Sartre, 1956; Merleau-Ponty, 1962). As an embodied subject, I do not experience my body primarily as an object among other objects of the world. Rather than being an object for me-as-subject, my body as I live it represents my particular point of view on the world (Merleau-Ponty, 1962: 70). I am embodied not in the sense that I have a body — as I have an automobile, a house, or a pet — but in the sense that I exist or live my body (Toombs, 1992). In this respect the lived body is not the objective, physiological body that can be seen by others (or examined by means of various medical technologies) but, rather, the body that is the vehicle for seeing.

Furthermore, the lived body is the basic scheme of orientation, the center of one’s system of coordinates. I experience myself as the Here over against which everything else is There. As orientational locus in the world, my body