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A Dialogue between the Body Schema and the Body Image: A Case of Mild Athetoid Cerebral Palsy

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1. Introduction: My Condition[1]

I was born six weeks prematurely and a doctor decided to put me into an incubator. Unfortunately, the decision was wrong for me since the incubator did not provide enough oxygen; I was anoxic. No one knew what was wrong with me at that time. My mother came to realize that there could be something wrong with me when I was six to eight months old, because my head was never steady; I constantly held it to one side. She was worried about me because I was not good at suckling and then I would vomit up all the milk I drank. I was taken to the hospital and finally, when I was about ten months old, I was diagnosed as having mild athetoid cerebral palsy. My mother told these stories to me when I was older.

Cerebral palsy is a very complex condition and every individual with cerebral palsy is affected in different ways, experiencing different symptoms. What we can say is that cerebral palsy is believed to result from damage occurring to particular parts of the brain before, during, or after birth. In most cases, it is impossible to determine what specifically causes it. What is so significant about cerebral palsy that it needs explanation? The reason is that cerebral palsy has influenced, and continues to influence, my ways of seeing the world; it matters a great deal to me how I see myself and perceive my place in the world. Cerebral palsy is not only a physiological and neurological dysfunction, but also a way of experiencing the world. As a consequence of social relations, it also causes a type of psychosocial stigma.

My type of cerebral palsy is categorized as athetosis. According to Li and Arya (2022), athetosis is an involuntary movement of the body that appears regardless of the person's intention, due to a failure of normal control by the brain. It is also one of the major movement disorders within cerebral palsy. The movements of people with athetosis are specifically characterized by a slow twisting of the limbs and head and a frowning face (Proctor, 2022). Athetoid cerebral palsy affects my ability to control movement and coordination, and in particular, the ability to produce speech. In this paper, I shall explore my lived experiences with cerebral palsy.

1 My experience as a newborn baby is also described in *Abject Love: Undoing the Boundaries of Physical Disability* (Inahara, 2009: introduction).

2. My Lived Experience of Cerebral Palsy in the Hair Salon[2]

The way in which I perceive the world is based on the way in which I am embodied. My lived experience of cerebral palsy shapes my interpretation of myself, an interpretation that is based on those embodied perceptions that are related to my bodily movements and sensations. As a result, I see the world as reliant on the particularity of my body. A mutual pact is formed between my body and its world, a pact that enables my body to collaborate in the world in a way that is determined by the way my condition is embodied. Consequently, I am embodied differently from able-bodied others and I see the world in a particular way, that is, in terms of experiencing my bodily difference.

My cerebral palsy affects the way in which I experience modes of embodiment, such as walking, talking and sitting still. For example, owing to my condition, I am not able to control my neck and head movements. When I have a haircut, I always feel nervous because I know that I cannot stop my neck flinching, and it is very difficult for my hairdresser to cut my hair. Although I like being dressed up and having a nice hairdo, I just do not like sitting in a chair at the hair salon. Moreover, I have to look at my own image in a mirror, casting my neck under a spell of immobility. I often imagine what I should do at the hairdresser's, and I am also very aware of my head moving involuntarily. Since I am not able to position my neck as expected in any of these ways, the nature of my experience of having a haircut is shaped differently from others. While others seem to enjoy their time at the salon, it is difficult for me to inhabit the same world that they do. Despite the fact that I was primarily uneasy about my inability to control my neck movement, I now accept it as a part of myself. My neck movement has naturally adjusted over time to reflect the hairdresser's skill. I like my hairdresser in Kobe because he does not care about my neck movement; he never makes me talk whilst giving me a haircut. He seems to know that if I speak, my neck will move a lot. To me, the hair salon had become the place where I experience my own vulnerability, in much the same way as others may experience their vulnerabilities at a hospital where they cannot take control of their own bodies. The point I am making here is that my embodied experience informs my awareness of the world around me. I trust that the explanation above provides an insight into how the able-bodied world, which many people habitually take for granted, ignores the complexity, fluidity, multiplicity, and vulnerability of human embodiment.

3. Body Schema and Body Image: Cerebral Palsy and Consciousness

According to the French phenomenological philosopher Maurice Merleau-Ponty (2014 [1945]), the body is not an object, but rather a subject who knows the world. The subject asks an initial question: "Who am I?", with the body open to the world. I argue that Merleau-Ponty's work exposes philosophy to emotional, expressive, perceptual, and sensual drives, to other people, and to the lived world. Against the conventional view of the body as a biomedical object or as a frame of consciousness, Merleau-Ponty demonstrates that I am my body. There is no ontological separation between the experiencing I and the body as I live it. Indeed, the lived body is my intentional opening to the world. Cerebral palsy is seen as an abnormal way of being-in-the-world, which can be understood, but only as something that is 'difficult', and where

2 Similar situations have happened to me in the dental clinic, ENT clinics, eye clinic and many other places. I am really bad at health checkups. When it comes to injections and blood sampling, my body stiffens and I get so nervous that I have even fainted. I am worried ahead of time about what to do if I have an involuntary movement at the moment when the needle of the syringe sticks in to me. My experience in the hair salon is also described in *Abject Love: Undoing the Boundaries of Physical Disability* (Inahara, 2009: introduction).

the deviance requires in addition a causal explanation, either in medical terms or in terms of early development. The experience of cerebral palsy is a substantial part of my existence, and it raises significant philosophical questions. Using phenomenology, the philosophical method for first-person narrative, I explore how cerebral palsy modifies my body, the values, and the world.

In *Phenomenology of Perception*, Merleau-Ponty (2014 [1945]) introduces the notion of the body schema to draw attention to our lived experiences of our embodied selves in relation to the world. Such a relation includes our sense of our body in the face of the tasks we perform. In *How the Body Shapes the Mind*, Shaun Gallagher (2005), an American philosopher known for his work on embodied cognition and psychopathology, argues that we need a distinction between body schema and body image, and he investigates the complex relationship between the two concepts. Gallagher argues that body schema and body image refer to two different but closely related systems. Gallagher (2005) suggests the following distinction between the two: 1) body schema as a system of sensory-motor capacities that constantly regulate posture and movement and function without reflective awareness or the necessity of perceptual monitoring; 2) body image as a system of perceptions, attitudes, and beliefs relating to one's own body. This requires and awareness of one's body as an object in space and some reflective monitoring and directions of bodily movements. Thus, Gallagher argues that a conceptual distinction between body image and body schema are helpful in working out their functional differences. However, the conceptual distinction should not imply that on the behavioral level the image and schema are unconnected or that they do not sometimes affect one another.

To develop the distinction further and to illuminate the interrelations of body image and schema, this paper examines my case, a subject with a body schema and body image of mild athetoid cerebral palsy. In order to undertake this study, I shall draw attention to two elements within the notion of body image. In one case we become aware of our bodies, for example when a learning new skill; in other cases, this awareness of our bodies is accompanied by consciousness of our bodies as they appear or would appear to others. This is the more everyday sense of body image, and by feelings such self-consciousness elicits. And such self-consciousness can disrupt both pre-reflective competence and deliberate bodily movements.

Shogo Tanaka (2021: 76-8), a Japanese philosopher who has been exploring the phenomenology of the body, compares the cases of Schneider and Ian Waterman in terms of the body schema and body image. Schneider suffered an occipital injury during World War I, the effects of which resulted in the various symptoms. He is described as a case by the neurologist Goldstein and the psychologist Gelb, and Merleau-Ponty discusses and explains his body schema. Schneider's symptoms can be divided into two categories: what he can do and what he cannot do (Merleau-Ponty, 2012[1945]: 105-6, and Tanaka 2021: 76-8):

What he can do:
- take a matchstick out of a box and lighting it on fire
- reach his hand to the site of a mosquito bite and scratches it.
- take a handkerchief out of his pocket and blow his nose.

What he cannot do:
- identify a body part when touched by another person.
- move a body part when asked to do so.
- tell where his nose is when asked to touch it

Schneider's case can be thought of as a case in which the body schema remains but the body image in first sense is missing for him. For him, the body does not appear as an object he can manipulate, even though it is the subject of habitual and concrete actions. Thus, there seems to be a difference between body schema and body image in this sense not only in the definition of the terms and concepts, but also as pathology.

Jonathan Cole (1995), a British neurophysiologist, has studied Ian Waterman's case using a phenomenological lens. Waterman was a butcher by trade, and one day at work he accidentally cut his hand with a knife. Unfortunately, he contracted some kind of virus from the wound and suffered neurological damage as a result. The neuropathy was very specific. The patient had a loss of tactile and proprioceptive sensation from the neck down (afferent tract blockade) and no somatosensory feedback at all. Waterman began rehabilitation despite the loss of somatosensory perception from the neck down. At first, he started with moving his hands. However, to move his hand, he had two requirements: he had to stare at the hand he was moving, and he had to look at the hand he was moving. He was able to move his hand not only by staring at it, but also by visualizing it in his mind. He gradually expanded the range of his movements to include eating, writing, and walking, and relearned the movements he had been unable to perform. He was not able to move his body as easily as he could when he was able-bodied, but it required a lot of procedures, such as gazing and imagining.

Thus, Waterman's symptom is a different type of pathology from Schneider's. Schneider can perform unconscious movements (scratching his arm, bringing his hand to his nose), but once he becomes aware of his body, he is suddenly unable to perform movements. Waterman, on the other hand, is the opposite: it is nearly impossible to perform a physical movement unconsciously, and he must first become aware of his body and visualize it before performing the movement. The difference between body schema and body image is 'consciousness'. The two are symmetrical in the way they lack body image and body schema. The two cases can be seen as examples of extremes. Schneider had a body schema, but not a body image. Waterman had a body image but not a body schema.

I can offer some examples that demonstrate the difference between body schema and body image from my own case. When I speak of bodily movement, I think of movement within my physical space. For example, when I want to have a glass of wine on the table, I first raise my arm 90 degrees to the side and then move it forward another 90 degrees to reach the wineglass. However, there is a more unconscious and direct physical movement that underlies this conscious and objective movement. It is a spatial movement in which the environment and I are attached to each other as 'wholeness', so to speak, in which I and the environment are changing in phase with each other's movements. I cannot hold a wineglass with my hand, which has involuntary movements. A wineglass has a unique shape and its structure is unstable for my hands. Generally speaking, when people hold a wineglass, they hold its stem. I can imagine supporting the stem with my thumb, index finger, and middle finger. In reality, however, just looking at a wineglass makes me stiff. I imagine my hands flailing and the wine spilling out. Then my whole body feels uncomfortable with the wineglass. It is very embarrassing, but in a fancy restaurant I ask a hall staff: "Excuse me, could you please pour me the wine into a stemless and stable glass?" I feel the similar discomfort everywhere in my daily life: in a McDonald's shop (I cannot carry items to my seat on a tray), in lounges at airport (I cannot drink a cap of coffee because the space and height between the couch and table do not fit my body, and

I cannot hold the cup and carry it to my mouth). At my home and my office, furniture, tableware, and everything are set up for my comfort, so I can relax and be myself in that environment. One thing this shows is that the possibility of a pre-reflective body schema enabling habitual negotiation of the environment; depends on a relation that 'fits', a relation between the body concerned and the physical environment, in other words, a body image is necessary.

When such a body image is lacking, the body requires difficult conscious manipulation, but it also shows something else. The discomfort caused by the gaze of others makes both the pre-reflective and the deliberative action hard to undertake. What I do not need to be conscious of is the ability to relax and smooth my movements in situations where habitual movements do not require special attention, as in my home and my office. In my case, there are many cases where I perform complex movements that demand attention. The image of knocking over a wineglass or spilling a glass of wine ahead of time comes to mind, and my body stiffens. Especially when performing a certain action in response to a request from another person, it is necessary to move the body consciously. In this case, a specific part of the body or the entire body is first imagined as an object of conscious orientation, as a movement is executed. Therefore, it is not possible to perform this type of movement unless the pre-reflective body schema is established. Movement is inhibited by a conscious awareness of my body image, as in the instances when I imagine knocking over the wineglass, causing me discomfort.

Despite the effects of cerebral palsy, I have a controlled posture and movement by consciously monitoring my position with my hairdresser at the hair salon. I suggest that, in this case, control over posture and movement were achieved by a partial and imperfect functional substitution of body image for body schema. As Gallagher and Cole (1995) point out, there is an issue to explore in a case of an impaired body schema in relation to body image. The body image, as a "reflective intentional system", generally represents the body as one's own body that belongs to oneself. It provides a sense of being self. However, in my case, I am alienated from a specific part of my own body, and that part is experienced as uncontrolled or controlled by my hairdresser. I am aware of it as it is for another. In contrast to both able-bodied and disabled experiences of body image, the body schema consists of a system of pre-personal, anonymous processes. Even in cases of intentional movement in the hair salon, my bodily adjustments that subtend balance and posture are not subject to my personal decision. Rather, various neural motor programs command muscle groups to make automatic schematic adjustments that remain below the threshold of my awareness and outside of my control. Body image involves a subjective, conceptual, and articulated perception of the body in so far as thought, attention, and emotional evaluation attend to only one part of the body at a time. It is also possible that as a set of beliefs or attitudes about the body, the body image can involve inconsistency or contradictions as it has multiple strands. The body schema, on the other hand, works in a more holistic way.

4. Why Do We Need Phenomenology of Cerebral Palsy?

No two people with cerebral palsy are ever identical as each person's lived experience raises questions about how people with cerebral palsy perceive themselves and how much this depends on their own bodily differences and on their social relations with others. Tetsuya Kono (2015: chap.4), a Japanese philosopher who has been working on special education for children with disabilities, suggests that Merleau-Ponty's phenomenology provides a conceptual framework for exploring the lived experience of people with cerebral palsy. He maintains that the treatment

of cerebral palsy needs to see any behavior as part of a whole structure of embodiment and the person's response to others in a social world. From the standpoint of phenomenology, Kono (2015) asks himself the question: "what is the body?" and to use this idea in education, rehabilitation and welfare for people with disabilities. He proposes a pedagogy from the perspective of ecological phenomenology, which adds ecological psychology to phenomenology.

There are problems with the modern natural science view of reductionism and body/mind dualism. Therefore, in order to examine education and rehabilitation, Kono suggests that we have to fundamentally change our way of thinking from the view of the body. Changing the view of the body means at the same time questioning the nature of treatment, training and education, which also means questioning the relationship between professionals and the children and parents concerned. Such a questioning of the body leads to a questioning of treatment and education and ultimately to the questioning of social relations. Kono states that the term "ecological" refers to a position that always attempts to view the activities of living organisms in interaction with their habitats. Kono's position assumes the perspective of the person concerned as a subject who perceives, moves and lives in the world, and thoroughly pursues the idea that all human capacities are established in an interaction of the environment and the physical subject. This ecological perspective and a phenomenological view of things based on the person's experience are effective in the rehabilitation and education of children and people with disabilities. In connection with this, Kono emphasizes the importance of the person concerned understanding their own disability and creating their own ways of coping with it.

In conventional disability studies, cerebral palsy has been viewed in two ways, the medical and the social models. A British sociologist of disability, Michael Oliver (2009) states:

> The whole medical and rehabilitation enterprise is founded upon an ideology of normality and this has far reaching implications for rehabilitation and treatment. Its aim is to restore the disabled person to normality, whatever that may mean. (Oliver, 2009: 24)

Oliver argues that the medical model regards disability as a personal tragedy for an individual and that what is required is a means to enable to person to return to 'normal'. I am a good example of Oliver's criticism of the 'medicine and rehabilitation enterprise: I want to hold a wineglass without calling attention to myself; I know my posture and movement will never be 'normal'. I agree with Oliver that the medical model of impairment, which perpetuates the idea that individuals are expected to be 'amended' or 'normalized' through some forms of medical intervention, is inadequate when applied to cerebral palsy. According to the social model developed by Oliver and many others, disability is all the things that impose restrictions on people with disabilities; ranging from individual prejudice to social discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements. Furthermore, the consequences of this failure do not simply and randomly fall on individuals but systematically upon people with disabilities as a social group who experience this failure as discrimination institutionalized throughout society.

The social model of disability, as Oliver maintains, places the responsibility for the problems people with disabilities face on society, rather than the fault of the individual. The social model suggests that disability is a form of social oppression by the able-bodied world and has little to

do with the body itself; ironically that is precisely what the social model insists; disablement is nothing to do with the body, it is a consequence of social oppression. However, the social model denies impairment is closely related to the body. I experience bodily restrictions as well as social oppression and therefore argue that embodiment must be placed at the heart of disability discourse. In particular, my awareness of the whole body needs to be recognized as significant in the study of disability and impairment. A British sociologist of disability, Nicholas Watson, questions the fixed notion of the social model. He points out that "[t]he social model is not without its critics, both from within the disability movement and from outside. Disabled feminists […] have argued that the social model, by excluding impairment, denies the personal" (Watson, 1998: 148). A conceptual 'middle ground' is needed; one that does not ignore the bodily reality of having a physical impairment but also does not reduce disability to a medical problem. And some disability theorists, such as Mairian Corker and Tom Shakespeare believe:

> that existing theories of disability – both radical and mainstream – are no longer adequate. Both the medical and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people's lives and knowledge. The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas. (Corker & Shakespeare, 2002: 15)

For me with cerebral palsy their problems must be understood from their own perspective, and as problems which cannot be normalized; an approach Kono (2015) and Cole, Inahara and Peckitt (2017) suggest, is a phenomenological one. The individual's experience of embodiment (in this case, cerebral palsy) must have a part in any debate about physical disability. Similarly, the social model often ignores the different experiences and embodiments of impairment. I have argued that both medical and social models ignore the first-person lived experience of being in the body with cerebral palsy, that the experience of having cerebral palsy does not 'fit' within the medical or social model. Nonetheless, attention to the phenomenological perspective of the person with cerebral palsy shows how elements of both the medical and social model are important. The possibility or not of pre-reflective smooth bodily engagement with the world, or successful deliberative engagement, depends on material characteristics of both body and world, and on the facilitation of non-normative possibilities, a social matter. However, it also depends on social acceptance of non-normative ways of acting so that the gaze of others does not inhibit behavior. We need material and social environments in which body schemas, and body images all work together to enable body/world interaction.

5. Concluding Remark

I have explored my examples to provide some perspective on my relation to my whole body. Following Kono (2015) Cole (1995 & 2004), and Leder (1990), an awareness of the whole body as lived is required when we explore the practical, creative and imaginative world of people with impairments. Medical discourses define symptoms and conditions of cerebral palsy. However, medical discourses do not approach "what it is like to be a person with cerebral palsy" and how each person's experience of cerebral palsy differs. I was forced to comply with the expectations of the able-bodied majority, but I could not exist if the specific requirements of my body were

ignored. It is important to understand that I need both medical and social support, informed by awareness of my body and my lived world. I have suggested that there is a need to focus on the dialogue between body schema and body images.

Rather that thinking of body schemas and body images as distinct concepts, we should perhaps think of them as connected or intertwined concepts. Our body schema was traditionally conceived of as proprioception – my ability to know my location in the world without looking at my body – whilst body image is awareness of my body as an object to manipulate together with how I feel about my body, (whether I think it is normal or abnormal and how others see it) However, I suggest that body schema is also a social concept. Its possibility rests on my body images, themselves socially anchored and on my material and social situation. The habitual and self-conscious bodily awareness slide into each other and change in different times and places. Thus, I have argued that body schema and body image are intertwined.

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Abstract

This paper reflects on my lived experience as a person with mild athetoid cerebral palsy and explains how my condition requires a phenomenological first-person narrative in order to be adequately understood. Shaun Gallagher (2005) has clarified Maurice Merleau-Ponty's notion of body schema by drawing a distinction between both body schema and body image. In this paper, I shall draw attention to two senses of body image and argue that body schema and the body image, in both senses, of a person with cerebral palsy are intertwined with each other. Following a phenomenological analysis of the body, I shall explore a dialogical relationship between body schema and body images within myself, and suggest that a phenomenological account of cerebral palsy (a phenomenological model of disability) is required for me to give an account of my embodied self.