

First Person Accounts of Cerebral Palsy; Adding Phenomenological to Medical and Social Models of Chronic Conditions

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Abstract

This paper considers the experiences of two of its authors who each live with a form congenital cerebral palsy and are also philosophers. They describe how their conditions require a first person narrative for full understanding and that the techniques they have developed to ameliorate their impairments are also personal and so not conventional medical interventions. We suggest that, while medical models of impairment and social models of disability are useful, a third phenomenological - model is also required, which allows an understanding of each person's subjective experience as well as their needs in relation to their condition. This may be particularly important for people with chronic conditions.

Introduction

Imagine you are engaged in some activity, reading in the back garden, when next door's dog is barking continually, preventing you becoming lost in the prose. Cerebral Palsy (CP) is somewhat like that, with uncontrollable forces constantly preventing you from becoming fully engaged in whatever you do, whether walking, writing, or making love and since CP is congenital, someone with CP will have known no other way of experiencing the world except as it being disrupted, constantly and unpredictable. Cerebral Palsy is not only a physiological and neurological dysfunction, but also a way of experiencing the world and, because of the consequences for interpersonal relatedness; it fosters a form of psychosocial stigma as well. It is defined as 'Cerebral Palsy is 'a persistent but not unchanging disorder of movement and posture due to dysfunction of brain, excepting that caused by progressive disease, present before its growth and development are completed. Many other clinical signs may be present [1]. We shall explore the lived world of CP where the body, the social, and the emotional coalesce. Our hope is to explore the differences between the general assumptions about CP and its subjective experience.

Most of our movements, such as walking, talking and tying shoe laces are skills we learn at an early age; we do not remember when we learnt, but we are proficient; we just do them. Walking is perhaps the most fundamental. Ordinarily we do not think about walking, our body just does it. But what if the body does not do as you wanted, but seemingly as it wanted, and what if it seemed to want chaos, from birth, so you knew no other situation? This is the case in some with CP; they have to be aware of their body all the time to move, and even to try to stay still. Their everyday life is dominated by a disruption of intention into action, agency, which most of us never even consider. Disruption of one's own movement by one's own brain, whilst not the essence of CP is one of its major characteristics. In order to demonstrate this, we shall explore the experiences of two people.

Firstly, some narrative fragments from a person whose CP has led to left sided hemiplegia. He is semi-paralyzed down his left side with poor control of volitional movement. All he can do reliably is, essentially, to 'grab and release' with his left hand in a fashion, and to walk with the help of a walking stick. Secondly, we give some observations of a person with athetoid CP; she has trouble holding herself in an upright and steady position to sit, and often shows involuntary movements, in particular when she speaks. Those with Athetoid CP have problems holding themselves in an erect, still position for sitting or walking, and invariably show involuntary movements. For some people with athetoid CP, it takes a lot concentration to get their hand to a particular place (like scratching their nose or reaching for a cup). Because of their increased muscle tone and problems holding a position, they may not be able to keep a grasp on objects (such as a cup, a glass, or a pen). For Minae, it takes a lot of work and concentration to speak.

Mickey's Tale: Questioning Incorporation

Case 1.1: There is no such thing as just going for a walk

As soon as I leave the house I have to alter my position and posture, making tiny alterations every second. Every movement of my foot, swing of the stick and grip on the stick handle has to be carefully coordinated. With no fluidity to walking, I need constant planning of every move. I am always aware of my body as an object to be controlled, not really 'part of me', and yet - and at the same time it is certainly 'my body' which I need to constantly reorganize.

The world, that is, my surrounding environment, appears as something hostile, which I am part of, but certainly not 'in.' The world is an object I continually manipulate, rather than being a friendly place and some where I feel at ease or at even at home. Within this hostile world, other people appear as obstacles to be avoided, not just because I fear bumping into them and hurting myself, and them. Even a hand offering help with shopping bags can appear hostile as it is an unexpected disruption to my 'walking plan'. I live in a world which assails the body and self, and I can only hope that the adjustments will allow me to survive.

To understand the experience of CP, we will employ a phenomenological approach. In part because we feel it a useful way to consider the lived experience of others, but also because two of the authors are philosophers, so their own experiences have been informed by their academic discipline. Having said this, phenomenology is, in a sense a method, to describe the lived experience of human beings, using its own way, rather than a philosophy. Phenomenology seeks description, which reveals the world as 'always already there', to use Heidegger's phrase, rather than explanation [2]. As Havi Carel states; 'Phenomenology is a philosophical approach advocating a description of lived experience and consciousness. It focuses on what it is like to exist as humans in a world. It is a simple, descriptive approach that rejects complex philosophical constructions of reality and puts aside questions about the nature of this reality. Instead, it focuses on the experience of an individual, the ways in which we perceive things (phenomena) as they appear to us [3].

Pertinent to this are the notions of ready and present. The ready is the world of available, the useful, the objects which one can use, be it a computer keyboard, piano or chess piece. The 'present' refers to things which are not usable, for whatever reason. For Mickey the world is diminished in the ready and expanded in the present. However, before examining at this further we wish to return to the walker.

Mickey has to adjust his body constantly, even though he never knows what adjustments exactly will have to be made or if they will work. Because he has mobility on one side and not the other, his experience of the world is fractured. On the right side, the side that works, there is the world that can be engaged with, what the phenomenologist Martin Heidegger called 'readiness-to-hand'.

The hammering does not simply have the knowledge about the hammer's character as equipment, but it has appropriated this equipment in a way that could not possibly be more suitable the more we seize hold of it and use it the more primordial does our relationship to it become, and the more unwieldy is it encountered as that which it is - as equipment. The hammering itself uncovers

the specific 'manipulability' of the hammer. The kind of being which equipment possesses - in which it manifests itself in its own right - we call readiness-to-hand (BT: 69).

For Mickey, objects on the right side are available, they can be used and enjoyed, but on the left side only unusable things exist, in an environment which one cannot really enjoy but has to be negotiated with great care. Worse still, things on the left assault Mickey, forcing him to constantly adjust his posture, stance and plans; they merely disrupt his ability to get from A to B, things on the left cannot be usually employed, they are merely things. Mickey experiences his right and left side as if they were two components of a machine that just did not work together, and their being 'broken', for want of a better term means that he lacks integration with his surroundings. It is difficult to describe Mickey's agency, it is not just that his agency is disrupted, or split; his whole relationship with his left side is entirely different in character to his relationship with his right side. When Mickey was much younger this need to negotiate with his left and right side independently of each other created a sense of physical bi-polarity, as if Mickey had two bodies to deal with and it affected agency, it could appear at times to Mickey as if he had two selves, one effortless in charge of the right side, the other hopelessly unable to take charge of the left. After thirty-three years, Mickey's split embodied subjectivity has to some degree been incorporated, but enough only to make dealing with the world easier; there still is a fundamental disruption and disincorporation between Mickey and his body, self and world. The disabled person's life is a disturbed assignment. Because of the amount of attention he must give his body and the world, they feel alien to him. He exists in the physical world with other people but it appears foreign, he is merely a guest whilst others are in it and his body is foreign too. He lacks what Maurice Merleau-Ponty calls 'Incorporation'; If I want to get use a stick, I try by touching a few things with it, and eventually, I have it 'well in hand', I can see what things are 'within reach' or out of reach of my stick. There is no question here of a quick estimate or any comparison between the objective length of the stick and the stick and the objective distance away of the goal to be reached. To use to a hat, a car and a stick is to be transplanted into them, or conversely, to incorporate them into the bulk of our body [4].

With this passage Merleau-Ponty started a discourse about skills and abilities as something which the intentional agent 'incorporates' understood best by Drew Leder in his book *The Absent Body* [5]. Leder reminds us that it 'literally means to "bring within a body" ' as related to, although not the same as skill acquisition. Swimming, tennis, chess playing, these are all skills, they are learnt, through repetition and adaptation to the point when they become almost automatic, done 'without thinking'. Most people 'incorporate,' make something such as a backpack or shopping bag 'part of me', but for the walker, the disruptive and unpredictable nature of his CP renders such incorporation impossible. He cannot grasp a skill because of his body; there can be no 'incorporation', despite his desire to. Iris Marion Young discussed this inability to acquire skills as 'inhibited intentionality' [6]. Merleau-Ponty suggests that to every action a person brings their whole situation; people have not only a physical and experiencing body, but also have histories and thoughts about the past and future. Whatever a person does, they do as situated subjects. This works the other way for the walker. After a failed attempt to grasp the cane, the walker may try again, but each

failure reminds him of other times when he failed to complete such an action. Trying a second time, he may begin the task thinking that 'I can do this, but memories of past failures turn that 'I can' into an 'I cannot' and induce him to withhold the necessary bodily orientation to accomplish the task. He fails because the very need to adjust and predict his involuntary bodily disruptions turn his failure to grasp the walking stick into a self-fulfilling prophesy. What cannot be over emphasized is the existential nature of inhibited intentionality. The difficulties the walker faces threatens not only his agency, his ability to commune with other human beings, but also his very existence. Walking down the street is about way more than just walking. Inhibited intentionality shrinks one's social world.

Case 1.2: 'Curing' Michey's posture

I have to go to the orthotics department almost every month. Each time a new pair of shoes, with a new style, is suggested. But these give me a new gait which does not fit to my body. Each pair makes my leg move in a way that I do not want my body to move, a way that seems unnatural to me.

One day, I begged the orthotics specialist to make a pair of shoes in an old style I could wear without pain. Unfortunately this specialist said: "You won't be able to walk very soon if you do not fix your posture and your way of walking. So I will make a new pair with a new design for you". As I listened I realized that the man was talking about Michey's future, but not about the Michey who stood in front of him, the Michey of the present. In addition, the specialist cared about my posture and my leg movements but not about my walking and my whole bod. If I do not have a right pair of shoes for me, I cannot walk and eventually I become socially isolated. I just want to be in the present!

Whilst trying to help Michey adopt a 'normal posture', the orthotics specialist ejects Michey from the world, by making his body unheimlich, something which is part of him and yet not part of him. When he wears his surgically designed shoes, he is no longer a being-in-the-world, no longer part of the world, despite physically existing in it. He cannot deny that it is his body that uses the shoes, yet it is not his bodily way of being, not how he expects to experience the world. The shoes which were meant to enable to lead a 'normal posture' have exiled him from his life. Had the orthotics specialist been more empathetic, he may have known what Michey goes through when he wears the surgically designed shoes and then he might have made a pair of shoes which allows Michey to walk. This empathy, however, requires a creative and imaginative step, since Michey's world is unlikely to have been experienced or even considered by the orthotist. This requirement for such a process, based on the lived experience of the person with CP, is one reason we proffer a phenomenological approach.

Minae's Tale: Questioning Normative Intelligibility and Fluency

Case 2.1: An able-bodied or able-spoken normative?

When I volunteered to be a guinea pig for clinical practices for fourth year speech and language pathology students in Australia, I felt uneasy. They wanted me to pronounce each word in the Received Australian Phonological Standard correctly, but I could not. Worse, when the students looked at the patterns of vowels and consonants

which I could produce, I found it even more very difficult. When the students asked me to pronounce words which start 'p', 'b', 't', 'd', 'k', and 'g', they found problems with my way of distinguishing 'p' and 'b'. They tried to fix my pronunciation. I found it very difficult because my first language is Japanese and I have little knowledge of English phonology. They said that 'p' was a voiceless stop and that 'pat' and 'bat' sound different. I thought I had pronounced 'p' and 'b' differently, even when, obviously, they could not distinguish my pronunciations of 'p' and 'b'. When I tried to pronounce them correctly, my body froze up and could not speak at all.

Communicating is a big issue for Minae. She moves her facial muscles into the right position to allow her to speak. She understands normal pronunciations of English and Japanese languages and knows she does not pronounce them correctly. It is impossible for her to pronounce these words as the students advised because she has so many problems moving her mouth to form words correctly. She also has problems with processing sound. When she hears background noise, she cannot focus on listening to people speaking and cannot speak to them with ease. Trying to improve the movements of her mouth and tongue, which some have suggested, is not helpful, since she has developed her own way of communicating and her facial muscles have adapted to certain ways of use. When students asked her to say words, to close her mouth, or to stick out her tongue, she found it difficult, because her whole body froze up because she felt nervous. Minae might be helped by a social setting where she feels relaxed and comfortable. However, in reality, society does not work for her whereas computer technology, in particular the internet, does help. To help her communicate more effectively, it is less important to fix her speech than to help with her needs, for alternative technological devices, a quiet space, and other methods of making her feel relaxed. Minae consider that the e-mail and online chat systems relieve the frustration of ambiguous communication on both sides.

Case 2.2: There is no such a thing as just giving a speech

When I give a talk at a workshop or a conference, I always feel uneasy because I not only feel nervous like everyone else, but also I know I am going to be frustrated at myself. Of course, it might be because English is a second language to me, but it is not only that. When I speak, I have to think of which words I can pronounce easily. Even if I want to say more complex terms and long sentences, I cannot. I avoid t words I cannot pronounce and I make my speech very short, and so shorten my thoughts and ideas. My thoughts and arguments are thus constrained not by knowledge or my creativity but by the link between me and the vocalization part of my brain.

When I hear noise during my speech, it disrupts my whole self: I cannot continue speaking at all, since my body shuts down. It is as if my brain just ordered me to stop speaking and to acquiesce to a forced silence, because my brain assumes that no-one can hear my voice over the noise. I feel uneasy with people who feel uncomfortable asking me to repeat what I said, and being with those who simply cannot understand me. Moreover, when I speak, my body moves involuntarily, jerking back and forth, from left to right. Some people have assumed that I might be drunk, with my unintelligible speech and involuntary movements. Without a signifier - a wheelchair, a walking stick or a guide dog I have nothing to indicate my impairment.

Similar speech disruptions can be found in personal accounts of stuttering. For example, Dale F Williams' Stuttering Recovery:

Personal and Empirical Perspectives states; for people who stutter, however, the disorder is far more than disfluency. It is also anxiety, worry, guilt, shame, self-consciousness, and a host of other auxiliary features. It is energy spent trying to hide disfluencies, be it via bodily movement, the rephrasing of utterances, substituting words, or any number of other behaviors that individuals have employed for this purpose. In other words, people who stutter deal with not only their speech, but also with secondary behaviors, emotions, attitudes, and fears about speaking [7].

As Williams mentions above, these fears are due to others and how they perceive people who stutter, something Minae also experiences when speaking in front of people. So before she gives a paper, she explains her disability and her vocal condition to her audience and asks them to read the subtitles of her speech on the computer screen using PowerPoint. Though common amongst scientists this remains unusual in philosophy. Her audience often pays attention to the screen, and the conference room is usually quiet.

It is, however, not always the case in her day-to-day life. For example, when she tried to ask for directions to Kings Cross Station in London, she wrote down on a small piece of paper: "I have a physical disability, in particular, speech impairment, and cannot speak to you. Could you please tell me where Kings Cross Station is?" It was a small lie since she could speak. However, she felt uneasy speaking in a public space, such as in busy London, because she assumed that people would be unable to understand what she was saying and so found it easier to be mute. She also considered how her whole body would freeze up if her speech was rejected by the listener. When Minae tried to get attention, most people just ignored her, before someone stopped and read it. She wondered if, in the UK, she looks East Asian and so could have been mistaken for a tourist. She also wondered if it would have been easier for her if she was recognized as a disabled person, because then people might have treated her better and not been shocked. She does not want to scare people.

Minae's bodily disruptions appear first in the lips, tongue, and jaw, and quickly spread to other parts of the face, head and neck and then the whole body. Pain from contractions of her neck muscles, over which she has no control, adds to the irregular and jerky movements which block speech further. Tremor is the first to appear, and then her body freezes up. It often begins if she thinks her speech is not intelligible and unacceptable to others, or as she tries to regain control of her speech and to make the message flowing. In turn, she feels out of control of her body or, more specifically, out of control of the ability to speak. Both the jerky movements and the fear of not-being-understood lead her into the darkness of being mute. In addition to her primary disruptions of movement and tremor, Minae also has more complex, secondary, disruptions.

These arise as reactions to the fear of not-being-understood. Minae can build up fear from the response of her listeners and tries to avoid unintelligibility, often substituting words that are easier to pronounce for ones she fears too difficult to say. Sometimes, she avoids talking altogether. She tries to cover up her condition; for instance a hand over the mouth while talking or writing notes. Minae's fear is people's assumption that, like the controversial Sapir-Whorf hypothesis, our thoughts are determined by our language. American linguists Edward Sapir and Benjamin Lee Whorf studied the relationship between language and thought, though neither of them wrote the hypothesis

bearing their name, nor supported it with empirical evidence and this area remains controversial [8,9]. The stronger theory suggests that language forms the way in which we think and understand the world and the weaker that language influences our thoughts.

Merleau-Ponty argues that our thoughts lead our speech, and that speech is a way of articulating our thoughts. He argues that there is something added on to our thoughts to make our inner ideas communicable to others; by our adopting a certain linguistic way. For Merleau-Ponty, the subject is not a 'speaking' one but a 'thinking' one; speech does not merely convey thought, but rather brings about or fulfils it. Even so, he does not define thought and language. For Minae, there are times when she cannot identify certain words until she has positioned herself in either an English or Japanese linguistic space, and also there are times when she cannot pronounce certain words and she needs to think of other words that are easier for her to pronounce. A frustration is that though her thoughts are not constrained by language, their communication is.

Towards a Phenomenology of CP

We have explored two people's physical limitations and their disruption between intention and action. In Michey's case, his bodily incorporation with in the world is constantly disrupted, while for Minae people's reactions to her visible difference and her voice prevent a normal flow of communication and interpersonal relatedness. These are two amongst many different experiences of CP. Why should we explore them? Conventionally, impairment has been viewed in two ways, the medical and the social models; we want to suggest that the experiences of both Michey and Minae show the need for a third, phenomenological model.

The sociologist of disability studies, Mike Oliver, wrote: 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 [10].

Oliver maintains that the individual or medical model of disability considers disability as a personal tragedy for an individual and that what is required is a means to enable to person to return to 'normal'. Michey and Minae are good examples of Oliver's criticism of the 'medicine and rehabilitation enterprise'. Michey just wants to obtain a pair of shoes to walk; he knows he will never be able to walk normally. Minae just want to communicate to people without calling attention to herself; she knows her speech will never be normal. They 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 both inadequate and wrong when applied to chronic impairment.

In distinction the social model of disability was developed by Oliver and others; [D] is ability, according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalized throughout society.

The social model of disability, as Oliver argues, locates the responsibility for the problems disabled people face within society, rather than with 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. But the social model does not deny impairment is closely related to the physical body. The social model does not deny that some illnesses have disabling consequences.

Michey and Minae, however, experience bodily restrictions as well as social oppression and therefore argue that embodiment must be placed at the heart of disability discourse. In particular, their awareness of the whole body needs to be recognized as significant in the study of disability and impairment. One way that the medical model fails is that it approaches impairment from the perspective of a normalized 'healthy' commonality. But for many with various bodily impairments their problems must be understood from their own perspective, and as problems which cannot be normalized, an approach we 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. It does not work for Michey and Minae who cannot transcend their bodies. Oliver also writes; the problem arises when doctors try to use their knowledge and skills to treat disability rather than illness. Disability as a long-term social state is not treatable medically and is certainly not curable. Hence many disabled people experience much medical intervention as, at best, inappropriate, and at worst, oppressive. The problem is that doctors are socialized by their own training into believing that they are 'experts' and accorded that role by society.

Michey and Minae suggest that medical and social models, which largely ignore the first-person lived experience of being disabled, are not true opposites and incomplete. Susan Wendell writes; the distinction between the biological reality of a disability [or impairment] and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability [11]. They are interactive not only in that complex interactions of social factors and our bodies affect health and functioning, but also in that social arrangements can make a biological condition more or less relevant to almost any situation.

Hughes and Paterson started connecting phenomenology with sociology. "A phenomenological sociology of the body - what Nick Crossley calls a 'carnal sociology of the body' - proposes a paradigm in which 'the social is embodied and the body is social'". If we take this argument/aphorism in relation to impairment and disability, then it would read that disability is embodied and impairment is social [12]. In *Still Lives: Narratives of Spinal Cord Injury*, Jonathan Cole explored the world of those who are living in a wheelchair, without what he called "the doctor/patient thing" getting in the way [13]. He interviewed twelve people with spinal cord injury, including Mike Oliver, and asked the phenomenological question, 'What it is like to live without sensation and movement in the body?' (And without continence and sexual function and often in pain). He found no single or simple answer. The twelve people had a similar impairment but many different experiences. The narratives move from a simple view of impairment and disability as an individual tragedy to disclose the possibilities and richness of life and lived experience available

to those living with spinal injuries. Like Cole's journey, we have explored Michey and Minae's cases that shows some perspectives on their relations to their whole bodies. Following Cole, the awareness of the whole body is required when we explore the creative and imaginative world of people with impairments. Medical discourse explains that CP is "a persistent but not unchanging disorder of movement and posture due to dysfunction of brain..." (Griffiths and Clegg). However, medical discourse does not approach what it is like to be a person with CP and how different each person's experience of CP is both Michey and Minae were forced to comply with the expectations of the able-bodied majority, but they could not exist if the specific requirements of their bodies were ignored. It is important to understand that they need medical support, informed by awareness of their bodies and their lived world.

No two people with CP are ever identical each person's embodied experience raises questions about how people with CP see themselves socially and how much this depends on their own bodily differences, and on their social relations with others. Tetsuya Kono, a Japanese philosopher who has been working on special education for children with CP, suggests that Merleau-Ponty's phenomenology provides a theoretical framework for exploring the lived experience of people with CP [14]. He maintains that the treatment of CP needs to see any behavior as part of a whole structure of embodiment and the person's response to others in a social world. We suggest that one requires, in addition to social and medical perspectives, some awareness of the first-person lived experience, informed by a phenomenological perspective, in this regard.

Concluding Remark

Disruption, whilst not the essence of CP is one of main characteristics of both spastic and athetoid CP. Each person with CP is aware of how their body moves and what they can do with their body in any given situation. We suggest that medical practice might be improved by awareness of the first-person lived experience of those with CP. Analyses based solely on the social model or the medical model and which ignore the individual's difference of experience of CP in experience of the body remain partial. The social model discounts embodied phenomena and medicine, whilst not ignoring individual experiences, is sometimes less sensitive to them, (after all, to 'manage' CP one does not necessarily need to know such experiences in detail). Though full accounts of first person experience may not always be required, some combination of medicine and social theories with phenomenologically informed first person approaches may prove fruitful. If the latter is adopted then able-bodied people may adjust their views of CP in creative and imaginative ways. As Oliver Sacks, wrote, "The study of disease, for the physician, demands the study of identity, the inner worlds that patients, under the spur of illness, create. But these worlds cannot be comprehended wholly from the observation of behavior, from the outside. In addition to the objective approach of the scientist, we must employ an inter subjective approach, to see the world with the eyes of the patient himself [15].

Author Involvement

JC invited MI and MP to write about their experiences. The first person accounts and views on medical, social and phenomenological models are largely theirs. JC edited and revised the original text. An earlier version of this paper appeared in *UTCP Uehiro Booklet*, No.2, 2013, pp.139 - 153, published in Japan.

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