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The Silent Biomedical Others

Intimacy, Communication, and Neurological Queerness

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Abstract

In this essay, I delineate the relationship between movement, thought, and the ability to speak. In neurology, the biomedical view constructs the image of the subaltern, a muted lifeform devoid of personality and whose life is not congruent with the concepts of autonomy and capacity. I propose to name these human beings "biomedical others." An anomaly, this subaltern, is an underside of the philosophical totalization of subjectivity. In the biomedical framework, others are devoid of speech. Medicine, its

institutes, and agents in the healthcare system speak to them. However, the lives of biomedical others are based on gestures, facial expressions, and body commands that are enacted as micro-gestures. The urgency to give voice to the biomedical others is the ethical task of this essay. They are namely voiceless and powerless, evoking a different kind of ethics: fragility, minority, and silence.

Keywords: biomedical others, disability, neurology, patient, subaltern.

Nemi biomedicinski drugi. Intimnost, komunikacija in nevrološka kvirnost

Povzetek

V prispevku orišem razmerje med gibanjem, mislijo in zmožnostjo govorjenja. V nevrologiji biomedicinski pogled konstruira podobo podrejenega, utišane življenjske forme brez osebnosti, življenje katere se ne ujema s pojmi avtonomije in sposobnosti. Takšna človeška bitja imenujem »biomedicinski drugi«. Tisto podrejeno je, kot anomalija, spodnja stran filozofske totalizacije subjektivnosti. Znotraj biomedicinskega okvira so drugi brez govorice. Medicina, njene ustanove in dejavniki znotraj zdravstvenega sistema govorijo njim. Vendar življenja biomedicinskih drugih temeljijo na kretnjah, obraznih izrazih in telesnih ukazih, ki se udejanjajo kot mikro-kretnje. Nuja, da damo glas biomedicinskim drugim, predstavlja etično nalogo pričujočega eseja. Kajti oni so brez glasu in brez moči, priklicujejo drugačno vrsto etike: krhkost, manjšinskost in tišino.

Ključne besede: biomedicinski drugi, invalidnost, nevrologija, pacient, podrejenost.

Hope is a muscle that allows us to connect.
Björk: "Atopos"

Imagine how your body is located in the space. Are you comfortable? We used to think that the world around us was shapeable, and that the fundamental evolutionary and cultural structures in the human body—the eye and the hand[1]—do not fail. The touching hand performs an initial gesture, uniting humans with other living creatures that are capable of organic animation. Higher cognitive capacities emerge from this power to move, constituting the subject and world around them. Philosophers argue that reality is inexplicably coupled with humans, providing them with various opportunities for action. The stone fits comfortably in the hand to throw it, the stick extends the hand to get fruit, and the cave is ready for the *homo sapiens* to move in and exploit nature's capabilities and resources (Paolo, Buhrmann, and Barandiaran 2017; Ingold 2000). A subject designed by philosophy is an integrated organism capable of using the crafts required by agrarian, marine, military, and technical inventions under the surveillance and control of intelligence and will (Lingis 1994, 58).

Intelligence and will master the body; the "normal" development implies corporeal apprenticeship and learning typical for all humans. By learning and mastering our bodies, we become ready to encounter a variety of sensorimotor contingencies, coping with a plastic gestural repertoire. Humans are supposed to "turn, stretch, walk, crouch, jump, hit, punch, recoil, lunge, shake, tremble, and leap" (Sheets-Johnstone 2011, 195).

1 Here, we can mention several approaches that guide this essay with regard to the questions of the body, gestures, and movement. Marie-José Mondzain, speaking about the vision of the image and the genesis of imagination during hominization, proceeds from the unique role of the transition from touch to vision (Mondzain 2010). Vilém Flusser echoes her in this, tracing the transformation of the "technological imagination" from the skin, ear, eye, and hand to the brain in the process of "total abstraction" of the human body (Flusser 1994). At the same time, there is no rejection of the body, as transhumanism suggests. On the contrary, having become an abstraction that entirely coincides with the philosophical vision of the subject, the body returns in a new quality. One of the scenarios of the lost and returned body may be the cyborgization project that has a history in science, technology, and culture (Kline 2009).

The coexistence of individuals in the lifeworld presupposes consistency and comprehensibility of experience. To become a full-fledged member of a community of humans, an individual must master certain cognitive, sensorimotor, cultural, and practical patterns of actions and utterances. To "become" a person, one must have a particular bodily mediated experience that others recognize as "normal" and epistemically accessible. We can see a specific refraction of topics inherent to phenomenology turned to medicine: the relations between "normal" and "sick" body, the meaning of pain and suffering at the intersection of individual and collective experience, health and illness in the cross-cultural context, existential aspects of healing, death and dying, violence and power, inequality and injustice (Becker 2004, 126). These topics have been touched upon by phenomenology before—for example, in the perspective of the problem of the balance of normal and pathological in the phenomenology of psychiatry.[2] However, the immanent normativism of classical phenomenology has been reinterpreted repeatedly, testifying to the weakening of the rigid transcendental universalism inherent in Husserl's project.

Cognitive psychology has called such universal possibilities of action *affordances*—structures dispersed in the environment, points of support for motor, symbolic, and social actions. Affordances are directly tied to the apparatus of a particular body; the repertoire of available interactions depends on the number of limbs and their physiological characteristics. The human body (or, more precisely, embodied consciousness) is a set of "I cans"; hence the able-bodiedness as the condition of possibility of being human.[3] Therefore, settling the world means being embodied in an environment characterized by the contexts and situations of practical actions. As cognitive scientists would say, an individual's life in an environment is based on attunement of sensorimotor structures as well as musculoskeletal and neurophysiological configurations.

2 Dan Zahavi wrote extensively about normativity "entrenched" into Husserl's phenomenology of intersubjectivity (Parnas and Zahavi 2000; Zahavi 1996; Zahavi 2005, 179–222).

3 S. Kay Toombs notes that the world we inhabit is designed for beings with upright postures. This disfigures the lived experience of "here" and "now," "distant" and "close" for those who use wheelchairs or other prostheses (Toombs 1995).

This result is an insoluble coupling with the world in its continuous practical development.

This view inevitably assumes the imprint of normativity: to be a living being/person/subject, one must be able to move, think, speak, and act. In this essay, I trace the connections between movement, thought, and ability to speak. I will begin with a generalized model of the philosophical understanding of the subject as an abstract system of thinking. Subsequently, I will contrast this normative picture with real biomedical cases. The underside of the totalized subject of philosophy is the biomedical other—a subject whose life is not congruent with the concepts of autonomy and capacity. Using illustrations from neurology, I will demonstrate that biomedical others are devoid of speech. Instead, medicine, its institutes, and agents in the healthcare system speak for them. Meanwhile, the lives of biomedical others are based on animations. However, their gestures, facial expressions, and body control are enacted at different levels, that is, at the level of micro-gestures. Micro-gestures require special hermeneutic efforts, which are often discarded in evidence-based medicine. Therefore, I declare giving voice to biomedical others as an ethical task of this essay. The ethics of biomedical others re-establishes the power of the powerless, the voice of the voiceless.

Portable mind and philosopher's stones

Philosophers have always avoided bodies. Whether it is a container, a prison, or a grave, incarnation is doomed to be something burdening and hindering the soul. Cartesian anxiety—anxiety about the interfering body, a lousy mediator between the mind and the world, perishable, sick, decaying—persecutes philosophy. The severe realization of philosophical intuition about the redundancy and uselessness of the body is the scientific model of the mind, claiming it to be an exhaustive scientific explanation of the soul. The Eastern and Western philosophies alike have not been able to explain for three and a half millennia what has been disenchanted and exposed by positive scientific knowledge. There is no soul; there are only reflexes of the brain, as Ivan Sechenov says. There is no mind, only a distributed system of impersonal

processes produces unconscious thoughts.[4] *The sciences of the artificial* readily provide metaphors, heuristics, and concepts for this ritual of desacralization of the last fortress of humanity. These secular rituals transform the mind into "a collection of world-structuring abilities which require an anti-individualistic picture" (Negarestani 2018, 163).

Meanwhile, questions remain regarding how the soul or its euphemism—cognitive processes—is understood in science and philosophy. What makes an individual human is not human in itself; that is what inhumanism claims. Yes, the human figure is important to us, but what gives her a special status in organic nature does not coincide with her species' narcissism (Brassier 2007, xi). To determine the point of intersection of abstract cognitive processes of the human species, we must not center them on consciousness and experience, culture, or artifacts. The self dissolves into a set of neurochemical commands that triggers disenchantment. I am a brain that dreams, and the dreamer does not exist; no one is nowhere or nowhen. The subjective experience of being present is predetermined by functional factors, such as the number and accuracy of input and output channels, the ability to modify the virtual environment, and the level of social interactivity—the ability to be recognized by others as a person in the virtual world. The point here is not abnormal encephalization as a condition and the effect of the development of capitalism (Pasquinelli 2016). It does not matter how the brain is designed or how the body is arranged and controlled by the brain. The brain is a command post for human computers. However, abstract computational operations are much

4 This thesis can summarize the significant part of classical and recent cognitive science. By their nature, cognitive processes—i.e., mental representations—can never be given to individual consciousness in experience; they carry out their work below the threshold of subjective consciousness. Accordingly, the mind is divided into subjective mental states and subpersonal cognitive processes occurring in the brain. This contributed to the transition in the framework of cognitivism from the problem of "mind–body" to the problem of "mind–mind," i.e., the problem of the correlation of unconscious cognitive processes and subjective consciousness arising as a result of these processes.

more important, giving birth to an architecture of pure disembodied thinking.

Alfonso Lingis remarks:

> In order to comprehend the passing patterns as consistent units and to recognize constellations of units that recur, one has to be able to command one's sensory organs to collect sensory perceptions in ordered ways, one has to be able to command one's posture and the forces in one's limbs, and one has to be able to command the moves with which one's body exposes itself to others and faces them. Thought, which finds itself commanded to think, also finds itself commanded to be in command. Thought must command its sensory-motor faculties to collect impressions that it can comprehend with requisite concepts and relate with cogent reasons. Thought must produce representations that function as commands that program the sensibility of the body, its movements among things, and its postures before others. (Lingis 1994, 17.)

Disembodied thinking transforms into a set of norms. One must think, act, and speak in the space of reason (Brassier 2011, 9). It does not matter what kind of body one has, what abilities are sewn into one's genome, or what diseases one suffers from. One can possess a fat, deaf, or blind body, stillborn or old body, and paralyzed or spastic body. Beyond this embodied medium, however, pure and abstract thinking constitutes the true core of subjectivity and agency. This core equalizes diverse forms of life and sense-making plugged in the space of reasons. Nevertheless, this supposedly humanistic view, by utilizing philosophical interfaces and affordances, begins by silencing the voices of those it speaks of and excludes from philosophical discourse.

These subjectivities, "humans by courtesy only" are seen from the standpoint of a detached theorist. This shadowy observer is a bearer of a unique perspective on the world, which allows us to talk about observed objectified subjects. Subjectivism without selfhood, whatever form it takes, objectifies the subject, her experience, corporeality, and affect. In biomedicine, it implies the view of the patient's body as a system of cells, tissues, and organs (Toombs 1992, 79). A static system is arranged according to the pathoanatomical,

pathophysiological, and microbiological nosology of evidence-based medicine, transparent to scientific manipulation.

Objectification mutes objectified forms of life.[5] It produces the illusion of a silent approval: yes, I, an inhuman, am just like that, and the opportunity to say something apodictic and generally meaningful about me is not available to me; only someone can talk about me who can show me: I am not me; I am something that does not belong to me and is beyond my control; I need someone who can look at me from nowhere and nowhen, with pure eidetics and abstraction. This view can be applied to medicine and healthcare. Medical communication appears to occur in a sterile space.[6] In this case, the patient seems to be "abstracted" from pain. The doctor, accordingly, "abstracts" from the patient's feelings, not feeling empathy for them, and translates the patient's complaints into the formal language of medical history. Instead, discourse dominates material and physiological sensations, and autonomy becomes a metaphysical attribute of the rational-psychological self, separated from the body.

Subalterns, androids, and biomedical others

In what cases does a loss of autonomy occur? Many people are familiar with the experience when, due to illness, even the most straightforward actions seem impossible when one finds herself temporarily unable to do the usual things. The inability to move one's body in space makes one feel defective and incomplete. One of the main theses of my paper is that philosophy avoids pathology and silences the voices of those whose existence is predetermined by their body's pathological, unorthodox, and non-normalized experience.[7]

5 Eric Cassell emphasizes that functional vision of illness leads the medical gaze away from the patient. He refers to a routine situation in an intensive care unit where the blinking and beeping of medical equipment is perceived as more credible than the patient's speech. The representation of the heart's dynamics in a cine-arteriogram is believed to be a truthful image of the heart, eventually substituting the natural heart (Cassell 2004, 21).

6 For a clear example of this kind of bioethical "abstractionism," see the compendium on the philosophy of medicine by Kazem Sadegh-Zadeh (2015, 123–124).

7 Critical disability studies contest the myth of the pure, autonomous, and self-sufficient body as a unity in space and time. Instead, many thinkers – such as Margrit

I prefer to focus on medical examples. According to Michel Foucault (1994), modern medicine is the science of individuals with a unique epistemological structure. In the hospital, doctors deal with individuals who, at the same time, are impersonal carriers of the disease. The patient's complaints and expressions are not as important in medicine as cryptograms and ciphers of the disease. This essence arises at the intersection of pathophysiological taxonomy. Illness is hidden in the patient and obscured by their experiences, knowledge, and body interventions. Here, we see the same obsessive abstractionism that ties medicine with philosophy. In a hospital, a patient is the carrier of the disease. In the clinic, the disease ties to this particular body whose functioning refracts and concretizes this abstraction. Consequently, this case is a curious example of pathology in a series of morphogenetic transformations of bodies and life forms. At any point, we are talking about mastering, maybe even colonizing, a sick body whose existence always associates with some supposed norm.

Colonization is a two-fold process. One is the expansion of the scientific image of humans. For example, when we experience a headache, we take nonsteroidal anti-inflammatory drugs. Pain or discomfort requires medical expertise and smoothing the psychological acceptance of one's medical condition. Explanations of physiological dysfunctions through experiential, social, or political phenomena are dismissed as unscientific; they are equated with "primitive" beliefs in malicious spirits that non-causally affect the human spirit. The other side is a consequence of the first. The patient's understanding of her experiences gets re-evaluated. It is no longer an immediate experience. It is a theoretical construct based on incorrect concepts that refer to nonexistent entities.

Once, the patient-doctor alliance was considered productive, both were equal participants in communication. Doctors were experts in the scientific understanding of medicine. The patient knew about her illness from the inside. Combined, these two images of the disease provided a synoptic vision. With the advent of evidence-based medicine, the role of the patient has decreased.

Shildrick (2013) – embrace the idea of "originary intercorporeality" as a condition of multifarious lifeforms beyond pathologization. However, these bodies were always muted, hidden from sight and cultural and political representation (Murphy 2001). The varied embodied experiences of "abnormal" subjects require a scrutinized and precise phenomenological analysis (Depraz 2020).

Compliance forced her to follow the doctor's therapeutic and preventive recommendations. Biologically understood health and normality are essential.

The muteness of embodied existence opens the way for medical procedures and manipulations. A "conspiracy of silence" enables it. The patient is not only denied the right to speak; understanding of her condition is limited from the outside with the help of a "communicative economy." This is a strategy of speaking and keeping silent about the course of the disease and ways of constructing a narrative. On the part of doctors, this is expressed in the regulation of communication: the use of rhetorical tricks, euphemisms, and allegories prevents multiple, overlapping, constantly changing uncertainties associated with the development of illness (Clemente 2015, 3–5).

The history of medicine lacks the perspective of a deterritorialized subject excluded from society as a recognizable personality (Casper 2020, 154). Instead, we need to see medicine "from below," from the patient's perspective (Porter 1985, 185). In this sense, she becomes an analogue of the wholly other modern philosophy, the biomedical other, devoid of speech. However, although disaffiliated, she often still has an intact consciousness and intention to manifest herself. The voiceless subject, *biomedical other*, asks for respect and recognition, whether she is a pediatric patient, a paralyzed patient, a quarantined or terminal patient, a patient in the palliative condition, a patient suffering from an inherited or genetic illness, a patient in a coma, a slowly deteriorating condition, or diagnosed with brain death.

They are all *subalterns* of evidence-based medicine and its unmourned victims. They are monsters: hybrids of life and death, born or living for a few days with a non-viable morphology; ugly creatures mixing unnatural forms; abominations violating the biological laws; the unclassifiable entities; "the unorthodox made flesh refusing to be normalized, neutralized, or homogenized" (Garland Thomson 1997, 24). Often, these patients are either non-verbal or do not respond to external stimuli. They have difficulties maintaining a sitting position and have problems with dressing and other daily activities. Patients' lives can induce shame and disgust.[8] They may also sweat or salivate. Due to

8 As Julia Kristeva says, "it is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders, positions,

vegetative disorders, their bodies do not control pelvic function. They may need special nutrition supplied through a gastrostomy, if normal feeding is impossible. Many patients require ventilation (tracheostomy), suction, probes, catheters, and coughers. Patients often die from pneumonia or aspiration when pieces of food or water enter the respiratory tract.

A good example is the locked-in syndrome. This condition can be caused by traumatic brain injury, stroke, and neurological and oncological diseases. For example, in the case of an aneurysm of the basilar artery, the nerves responsible for arbitrary movements are affected, except for those responsible for vertical eye movements. The syndrome can also occur with the development of neurodegenerative diseases, such as spinal muscular atrophy or amyotrophic lateral sclerosis. In these diseases, progressive damage to the motor neurons is accompanied by paralysis of the four limbs (quadriplegia) and muscle atrophy.

The fact that the "locked" subjects retain consciousness was realized by physicians, when they paid attention to the arbitrary eye movements of motionless bodies. Consciousness, shackled in a broken diving bell, is still capable of awareness, will, and communication, illustrating philosophical abstractionism. Before that, these patients were treated as "vegetables," being in a vegetative state or diagnosed with brain death, and therefore regarded as objects that can no longer be called humans.

Until recently, it was believed that a patient's life with complete paralysis was doomed to be a short period of painful existence, which would end in death from suffocation or food getting stuck in the throat or respiratory tract. However, since the 1970s, thanks to technologies and incorporations, such as iron lungs, gastrostomy and colostomy bags, artificial ventilation, and hydration devices, it has become possible to support and prolong patients' lives. Consciousness encapsulated in a motionless body is tormented by an inability to control its fragile shell. Therefore, it might be desirable to get rid of this shell and move the mind into a machine substance that will never get sick or die.

A midpoint scenario is to become a cyborg, a hybrid of humans, animals, and machines. However, these cyborgs do not enjoy beautiful polymorphic

rules. The in-between, the ambiguous, the composite." (Kristeva 1982, 4.) See also Mintz 2016.

bodies.[9] Yes, their bodies are hybrid and intertwined with technology; however, this is not a creative plexus of the living and the artificial. Technologies support the patient's identity and facilitate their involvement in social interactions. Technology is incorporated into the body rather than reassembling its boundaries. Some suggest interpreting the bodies of such patients as technobiological assemblages[10] connected to the social interfaces and institutions of medical services, the cognitive and sensorimotor capabilities of medical personnel, and social infrastructure. Their condition is caused by the need to maintain vital activities and restore "normal" functioning. Their lives are filled with pain and discomfort, perceived as technologically sustained and clinically prolonged dying. Therefore, they yield either rejection (abjection) or, as François Laruelle (2015, 46) asserts, pity—instead of compassion or empathy—with an alienating attitude. Their hybrid nature contrasts their experiences with the abstract subjects of philosophy; hence, the initial fault of philosophical thought:

> In place of man, of his real and absolutely singular essence, it [philosophy] employs anthropological, even androlological, images, and quasi-transcendental androids (the Cogito, ens creatum, Spirit, the I think, the Worker, the Unconscious, etc.). These are fictional beings responsible for populating the desert of anthropological screens,

9 See Siebers 2001. Similar ideas can be found in Drew Leder with his concept of bodily "dys-appearance." It takes place when the body appears to the subject as ill, bad, or disgusting. In normal healthy functioning of the body, it "dis-appears," that is, recedes to the background of daily activity, for example, while accomplishing routine tasks or moving. "Dys-appearance" forces the subject to draw attention to the body parts, which cease functioning or feel pain or inflammation. The task of medicine, then, is to enable "dis-appearance" by softening "dys-appearance," that is, alleviating suffering and increasing patients' quality of life (Leder 1990). Kristin Zeiler adds the aspect of "eu-appearance," which refers to the good, strong, well, and automatic functioning of a healthy body (Zeiler 2010).

10 As Kelly Fritsch says, "disabled people are entangled in multiple assemblages: the human-machine assemblages of wheelchairs, ventilators, or walkers; human-animal assemblages such as assistive animals like guide dogs; or disabled-abled assemblages of the disabled person and care attendant" (Fritsch 2010, 3). See the historical analysis of cyborg technologies in relation to disability and normalization in Mills 2011.

> shadows projected on the steep walls of Ideas, inhabitants of ideal caves. (Laruelle 2018, 5–6.)

Instead of living in a philosophical cave that eloquently illustrates philosophical myths, biomedical others are silent and disaffiliated. Their silence speaks more about the inconsistency of the obsessive norm than about many philosophical concepts of agency.

Wahaha and Wawawa: The echo of the subject

In neurology, one can find a strong belief that the gradual degradation of motor functions leads to the loss of autonomy and demise of personality in general. Movement is the basis of upright posture and redistribution of body weight in limbs. Typically, this contributes to the proprioceptive standing of the body in the environment. We do not refer to perceived movements that can be named and analyzed. Each step, according to Stamatia Portanova, is accompanied by a virtual multiplicity of elusive micro-movements that position the body between gravity and the skillful mastery of the body, flying, and falling (Portanova 2013, 9–10). In a step, each bodily gesture is dispersed into the diffracting heterogeneity of imperceptible microscopic movements of toes, ankles, knees, and legs—i.e., minor gestures, to use Erin Manning's concept (Manning 2016, 4). We observe primary movements in the bioelectric activity of the brain. For movement of the whole body, it is necessary to transmit signals from the limbs and surfaces of the body to the central nervous system and back (Sheets-Johnstone 2011, 396). In order for the immune system to recognize the body's boundaries and allow it to distinguish between "self" and "alien," it must move in the phase space of molecular forms (Varela 1994).

Thus, for a "healthy," undisturbed bodily movement to occur, it needs the connection of many nameless, unconscious processes that have nothing to do with verbalization and discursive assertion of the subject. Immobilization of the body during paralysis can lead to the demise of cognitive processes and, consequently, death of the self (Casper 2020, 155). The sought-after transcendental, which constitutes a subject in the material-discursive network of meaningful communication, still depends on the body and its location in the world.

From early childhood onwards, a person's self is formed in interaction with others by imitating gestures and facial expressions, as well as by creating meaningful communication structures. An individual is never left alone with himself, and, as the psychoanalyst Donald Winnicott believed, a child is alone only in the presence of others. A newborn needs a mother to maintain its homeostasis. The child's body temperature becomes the object of joint, dyadic regulation, for example, when a newborn is placed on the mother's breast (Tronick et al. 1998). The phenomenologically inspired hypothesis of "participatory sense-making," by Hanne De Jaeger and Ezequiel Di Paolo, states that the psychosocial development of an individual presupposes synchronization and coordination of their actions with others (De Jaegher and Di Paolo 2007). Inculturation, education, and training involve individuals in intersubjective practices and "guide" their life along the "entrenched" ontogenetic pathways.

Consequently, as the subject of her actions (*agens*), an individual undergoes what happens to her (*patiens*). Life reveals its dependence on the environment. Even the simplest organism needs nutrients scattered throughout the environment. It forces the lifeform to make minimal distinctions, using its body to transform neutral physical reality into a series of sedimentations. It is the idea of life as a creative process of transforming the system in an enabling environment as if nothing interferes. The system grows and develops, modifies itself and the world, and communicates with other systems.

However, life is only sometimes an unhindered multiplication of forms and ways of using one's body. Life involves fractures and interruptions, breaks and crises; deformed by disease or trauma, aging and dying body is also life. The disease reveals life's fragility and ontological instability: no matter how well-coordinated the system's self-maintenance processes are, they can permanently be disrupted, leading to disintegration. As applied to medicine, this means that we cannot proceed from the assumption of the autonomy and intactness of the patient. Illness entangles the subject with processes and events beyond her control, revealing the pathic/pathological experience[11] paradigm. Two

11 The most comprehensive approach to the problem of psychological experience can be found in Henri Maldiney (2007, 361). Pathic experience (from Greek πάθος,

aspects of illness can be distinguished: physiological and lived. While the disease is the subject of medical diagnosis and treatment, illness, by contrast, affects the subjectively lived experience. A simple example is the conflict of interpretations of the experience of illness. The same event can be evaluated "subjectively" from the patient's point of view and "objectively" from the point of view of biomedicine. If we suppose that the latter reduces the disease to physiological processes, the former initially evaluates it as an existential event directly related to the issues of life, death, and their meaning.

Without a body, there could be no thought. However, the patient's experience has not been voiced, even in this view. Since paralysis leads to the erosion of the psychological self, is there "someone" in this silent body who can be addressed and needs to speak and enunciate herself? Is there an articulated message to be communicated? According to some neurologists and clinicians, motor paralysis and neurological disability are accompanied by thought paralysis. Since there is no sensorimotor or musculoskeletal movement, there is no communication—the lived distinction between organism and environment vanishes as well as the meaningful interactions between them.

Tamara Cheremnova, who has lived most of her life in Soviet and Russian orphanages for disabled children with cerebral palsy, compared herself to an improperly programmed machine. She considers the ability for autonomous movement as the condition for a free, uninterrupted life:

> People! Healthy, normal, not crippled, non-masked, able to move on their feet, and control their hands! Breathe freely and rejoice that you are gifted with unimaginable wealth—the ability to independent and controlled movement! Feel yourself happy, as long as you do not depend on anyone! Do you want to think that a healthy self-managing

"suffering, passion, sensuality, affection") encompasses non-cognitive, embodied knowledge about the world, irreducible to the theoretical and realized beyond the distinction of subject and object. It is analogous to the receptivity, the "lived sense" of being in the world, and reveals a personal presence, pre-reflexive, but practically realizable knowledge about the world, or, in a broad sense, a sense of attunement to the world—not in the sense of gaining positive knowledge about it, but in a bodily mediated passive sense of being "here and now," which cannot be controlled by the individual.

> body is happy? Then, at least agree that this is the basis for happiness. (Cheremnova 2011; no pagination.)

Life without walkers opens the prospect of a happy life filled with traveling, educating, loving, acceptance, and beauty—life unconfined by the ugly homemade wheelchair. Feelings and effects of embodied life shape spatial and kinesthetic perceptions. Life joyfully moves toward the attractor and fearfully runs from the repeller. Emotional life is congruent with the sensorimotor structure of the body and spreads across a spectrum of differences beyond normalcy and health.

Once a subject deviates from the "normal" and "expected" trajectory of ontogenetic development from vulnerability to autonomy and self-sufficiency, her perception by others transitions from psychological to neurological. Devoid of autonomy and the ability to think rationally, with strict separation between the self-enclosed body and the exterior world, biomedical subjects compromise the idea of "healthy" normative embodiment. Hence, they are not perceived as cognitively intact, in control of their stable bodies or capable of impartial thinking. The subject loses human features and becomes an appendage of the disease, a silent witness to her degradation and death. The neurological patient is no longer an active subject—so close and so distant from "healthy" humanity; somebody and nobody; an unrecognizable presence. She is a passive observer who dutifully follows the destiny of her brain, becoming *neomorts* and *faux vivants*, medical curiosities. Who choses their own physiology?

The ability to speak and articulate oneself is associated with the ability to build a narrative, in which an individual acquires inner unity and accessibility to others. Simultaneously, it provides the ability to understand others. According to the developmental model proposed by Daniel Stern, the feeling of the verbal self emerges in infants aged 15–18 months. It is a subjective organizing position experienced as the self, and the other has a reserve of personal knowledge and experience about the world. This knowledge can be transmitted by using symbols. This part of subjectivity coincides with the acquisition of sense-making abilities. It is verbally shared with others. However, language only reinforces what has already occurred in other sensations of the infant's self. It only brings logical harmony and linearity to articulate her feelings and

experiences. In medicalized neurophysiological vision, empathy is reduced to the ability to build a "Theory of Mind, a model of others' internal motivations, emotions, and thoughts. "Theory of Mind" explains the behavior of others.[12] If one does not have such a model, even more so the ability to create it, one is doomed to perceive others as automatons, robots, or zombies, whose world is devoid of interiority.

Interestingly, this inability to understand and empathize with others is attributed to individuals with an autism spectrum disorder. They allegedly perceive others as soulless automatons who do not speak, but make noise, and do not act, but move in space according to simple algorithms (Grunsven 2020). At the same time, patients are turned into machines whose cognitive patterns can be reformatted, normalized, and disciplined with drugs, pedagogical techniques, and socialization.[13] The machine is a carrier of pathology and a neurological queer, and its vital activity is challenging to fit into the norms of sociality and human community. Such subjects are denied the right to talk about themselves; they are made *invisible*—reduced to a functional breakdown of neural processes and deprived of the right to autonomy due to illness. The one who cannot discursively comprehend the other and present themselves in rational discourse is not a human being.

12 Evan Thompson argues that in experiencing the other as an embodied living being, I perceive her in several dimensions: 1) as an animate lifeform; 2) as enclosed in an embodied existence (growth, development, aging, health and illness, strength and weakness); 3) as expressing subjective experiences; 4) as the center of spatial orientation; 5) as capable of volitional action (Thompson 2001). Therefore, the other is not a mechanism, but an organism living its life. The patient is not a machine with a broken part or impaired functioning, but a living being experiencing pain and suffering. These experiences set the dynamics of growth and development, states of health and illness, strength, infirmity, and dying. See also the phenomenological analysis of social cognition and empathy in clinical cases of schizophrenia and autism in Murakami 2013.

13 The founder of bioethics Van Rensselaer Potter developed a classical account of the human being as a far-from-equilibrium cybernetic machine (Potter 1970). He saw his theoretical project as a substitute for the dying survival instinct; hence, bioethics as a science of human biocybernetic machines is a kind of "prosthesis" grown by culture, society as well as scientific and technological infrastructure. For the history of the transformation of the scientific image of human to machine metaphors with regard to the example of cyberization of the brain, see Dupuy 2009.

Aya Kitō, a Japanese schoolgirl suffering from spinocerebellar ataxia, wrote in her diary about the difficulties of verbal articulation of speech, motor limitations, and the impossibility of participation in the community, drawing a direct analogy between herself and concentration camp prisoners. The slow progression of the disease in phases, gesture by gesture, micro-movement by micro-movement, takes away her ability to speak:

> I can't even talk loud anymore, and can only say one word at a time. I cannot even laugh at Wahahaha, and when I try to, it comes out as Wawawa. […] If someone says only one or two words a day, can you say that they are really leading a life as a member of society? . . . I am becoming that kind of person. (Kitō 2011, 76.)

This holds true for hard cerebral lesions, which create broken and disaffiliated identities of the "new wounded," as Catherine Malabou calls them: victims of traumatic brain injuries, tumors, patients with encephalitis or meningoencephalitis, degenerative brain diseases, cerebral palsy, amyotrophic lateral sclerosis, schizophrenia, and autism (Malabou 2012, 9–10). In part, they are the victims of their biological destiny. They are deprived of philosophical, ethical, and psychological personifications, which embrace the logic of totalization and bring to the identical, always enclosed self, contrasted with alterity and the other.

To be heard is to be seen; plenty of studies point to the multisensorial status of culture.[14] However, who listens? For Jean-Luc Nancy, hearing subjectivity by no means appears to have been pregiven. On the contrary, the listener should always be "on guard," since listening is the task of achieving the self in resonance, diffracting and returning in the echo of the integrity lost by the subject (Nancy 2007, 9). Nancy plays with the phrase "becoming all ears," saying that the listener is always just a presence seeking to establish connections with "self"—not with "self" as the "I" of the listening subject or the "Thou" of the heard, but bringing presence to itself. In the hearing experience, "self" turns out to be something absent and cannot become something that the subject can achieve. In

14 For example, Laura Marks claims that olfaction is closely tied to emotions, affects and "collective memory that remained elusive from images and words" (Marks 2002, 121).

contrast to the neurological view of a patient with residual subjectivity, hearing is problematic. The evoked hearing companion—physician, nurse, caregiver, sibling—turns out to be a resonance, an "echo of the subject," and not vice versa.

Speechless subjects, vegetative beings

Diseases reduce individuals to prostheses that mediate the development of pathology and endow a sick subject with the status of a subhuman, a non-place of speech, someone less desirable, less valuable, and less knowledgeable. As Melanie Yergeau says:

> Speech, as in words that can be heard coming out of human mouths; writing, as in words that are arranged so as to be read and meaningfully understood by people; intention, as in actions that not only carry a kind of purpose or intentional meaning, but also actions that also work to deduce goals and reflections from other people, all supposedly possessing neurotypical magical superpowers; emotions, imagination and socialization—I could go on. (Yergeau 2018, 14.)

Paralyzed lives are often lonely. Researchers have noted the risks of resocialization in patients with locked-in syndrome, which leads to depression and suicidal thoughts. The outline of their lives is formed by complete dependence on others—nurses, family members, and medical technologies—with the possibility of a sufficiently long life in this state. Owing to the complete lack of motor activity, except for saccadic eye movements or residual movements of individual limbs or body parts (one finger, cheek, eyelid), their lifeworld shrinks and becomes routine. They become accustomed to the atmosphere of hospital life with its characteristic nervousness, repetitiveness, and insufficient attention to their needs. Some patients complain that the medical staff treat them as pieces of furniture, objects, or cadavers that do not understand human speech or cannot respond to it.[15]

15 According to psychological studies, the paralyzed patients complain about being treated like vegetables, as being simple minded, babies, or infants (Nizzi,

Different countries have different practices of care for paralyzed patients. For example, in Japan, it is customary to keep patients at home because of the services of companies created by professional nurses and caregivers. Nurses support patients' lives. They monitor the functioning of artificial ventilation devices, listen to the patient's microgestural nonverbal signals, take her out for walks, and provide psychological support. The dependence of a paralyzed patient on the help of a nurse and/or family members becomes so deep that it is appropriate to talk about recreating her subjectivity in interactions with others. Moreover, having lost bodily motor control and locked inside it, the subject becomes even more social than before the illness.

In a study based on interviews with professional nurses working with patients with amyotrophic lateral sclerosis, Murakami showed how the patient's subjectivity reemerged in interactions (Murakami 2020). Patient's subjectivity is social and material-discursive. It arises as the disease progresses. The anthropologist Dominique Lestel asks:

> From what degree of disability or cerebral handicap can we consider a human being no longer a person but rather a purely vegetative lifeform? It is true that, compared to these cases, animals have better communicative social skills than people with disabilities, even though the former do not have psychosocial personalities. (Lestel 2014, 116.)

With paralysis and social deprivation, subjectivity fades simultaneously with the fading ability to move, speak, and express one's emotions. Nevertheless, communication becomes more intense, although it acquires more unusual features for a "healthy" person.

Goricheva, a late Soviet feminist and Eastern Orthodox philosopher, named the figures of transition from the unconscious to the conscious. Neurological disability shifts the boundary between cognitive impairment and unresponsiveness to stimuli. However, she outlines a series of cultural scapegoats: outcasts, criminals, prostitutes, demons, savages, clochards, women, Jews, and homosexuals (Goricheva 2010, 109). The modern figure of

Blandin, and Demertzi 2020).

the polymorphic Other is an animal. This silence discloses the unconditional acceptance of the world. Though remaining mute and speechless, a vegetative being completely articulates itself without linguistic mediation and without a recognizable self (Goricheva 2010, 117).

For some cognitive scientists, the world-directedness of embodied activity correspondingly implies a virtual bodily activity, such as in the cases of imperceptible movements and oscillations, covert non-muscular processes. To complete what the paralyzed patient wants to say or express, the nurse learns to read and decipher barely noticeable non-verbal signals in the patient's gaze—minor gestures of the biomedical other. Gradually, as the disease progresses, the immobilized patient loses the possibility of verbal and non-verbal articulation. The nurse knows the patient from when she can speak: her manner, intonation, and emotional repertoire. This establishes continuity between the patient's identity and that of the patient due to paralysis. Psychosocial identity implies the location "wherefrom one is talking" and "to whom one is talking." These places of interiority and exteriority are mutually constituted in *extimate* relationships, where the patient's silent subjectivity is reconstructed in a complex network of material-discursive relationships (Lestel 2014, 121). As Karen Barad claims, there is no absolute "inside" or "outside" except for the exteriority within; not *in*, but *of* the world constituted by the contingent separations and intimacies. The self emerges as an intimate relationship based on minor, silent gestures and movements. True, this is more of a nurse's monologue with herself than a genuine dialogue. However, this involves a high degree of empathy and emotional fusion with patients.

The fundamental existential problem faced by the locked-in is communication. Because of isolation within their bodies, it is challenging to say something, since they cannot use the speech apparatus outlined by Yergeau. Techniques for augmented and alternative communications remain to be used. In the classic locked-in syndrome, the arbitrary control of blinking or vertical eye movements is intact. Patients blink to give "yes" and "no" answers to questions or point at letters on alphabet boards for assisted reading (partner-assisted scanning). Alphabet boards are made of transparent material so that the assistant can follow the movements of the patient's eyes and help compile words from individual letters.

Patients usually want to say more than what they can express through the media available to them. Mediation in such cases intimately connects vital functions and their preservation. The difficulty here is that communication with assisted reading[16] is lengthy: it takes minutes to compose words from letters. In addition, when tracking the patient's eye movements, mistakes often occur and they have to start over. Recently, great hope has been pinned on the brain-computer interface and neuroimplants. For example, with the help of mental commands, the patient can select letters by controlling the cursor on the screen and give commands to a voice synthesizer that speaks "for" the patient as her interlocutor. Technologies do not simply participate in the re-emergence of the immobilized self. These are the prostheses and artificial organs of the constitutive dynamics of the self and its embodied interactions. Prostheses and biomedical technologies invent a condition, in which human bodies are seen as simultaneously disabled and enabled.

Coming out of the closet: Narrating medicine from below

We still do not know what it is like to be a patient with locked-in syndrome or how to live an imprisoned life. Only approximately can one guess what they feel and think from the autobiographies and stories of those who were able to overcome depression and suicidal thoughts, almost literally "coming out of the closet." An analogy with the queer coming out is not accidental. One needs to have a remarkable courage to declare themselves to society, to demand not just pity, but also recognition of personality as a full-fledged agent. Disability was not particularly noticeable until the middle of the 20th century, when the disability rights movement and activism declared itself. At the time, people with "abnormal" and "non-normalized" experiences of their bodies were deprived of subjectivity; they were not recognized as human beings. Their experience is still not pronounced and has not become available to "healthy" people who are lucky enough to use their bodies skillfully for statements, emotions, and actions. Meanwhile, such experience can teach us something. Since our empathy and communication mechanisms are rooted in recognizing

16 The "weakened" communication abilities force caregivers to extract meaning from the extremely few words typed with an alphabet board or speech-generating devices.

the other through her bodily movements and facial expressions, they fail when meeting a motionless and silent body confined to a bed or wheelchair.

Postcolonial theory discusses the oppressed, who has no opportunity to speak—not because she is mute or has nothing to say. Even vegetative organisms can express themselves in connection with others. No, she is silent because none of the media of speech and articulation available belong to her; she, as the other, does not have a native language. The latter is the language of the oppressor, conqueror, and colonizer. Therefore, she may have been unsuited for telling her truth and manifesting her experiences. Similarly, the language of medicine—at least its allopathic version—expresses the point of view of the doctor and the winner of the disease. This version of the Medical Gaze has no place for loss, death, or failure.

Therefore, the stories that medicine tells are stories from the winners' point of view: healers in an alliance with recovering patients. A neurological patient is the loser in this story, because she is not always lucky enough to become a member of the "remission society."[17] She is close to the subaltern, but cannot speak in connection with her physiological condition. At the same time, she does not give any reasons to exclude her from social life, to make her silent, invisible, and ultimately an inanimate, passive object.

A specific repertoire of cognitive abilities refers to having a particular body with a given set of characteristics and articulations of its constituent parts. Therefore, if we had a different body, our perceptions of the world would have been completely different. For example, if we did not have two hands, but three or five hands, or none, our interactions with the world would unfold differently. The habitual "malleability" of things for grasping gestures with our hands would be replaced by something completely different. We would not be monsters or anomalies in the world of compulsory normalcy silenced by its institutions and shared practices. Rather, we would be alternative instantiations of embodied situatedness in the world. It is necessary to recognize different

17 For Arthur Frank, remission society unites those who recover from cancer, attend cardiac recovery programs, diabetics and other chronic illness patients, those whose allergies and sensitivities require food restrictions and attentive self-monitoring, users of prostheses and artificial organs, and former addicts. In other words, they and their families were lucky to stay well through severe medical conditions (Frank 1995).

types and varieties of autonomy depending on the neurological and somatic organization of life forms or their interactions. In medicine, the subject's autonomy can turn into its seemingly complete opposite, vulnerability and fragility.

Cicely Saunders, the founding figure of the hospice movement, pointed out that Western societies pursue health, prosperity, security, and pleasures. Hence, questions of illness, suffering, and death should not be asked (Saunders 2006, 38). Terminal illness is considered unfair as a failure in medical knowledge. "Normal," "healthy," and "expected" life is fragile and unstable. However, severe disabilities and biomedical body alterations can enable growth and new possibilities.

This vulnerable and contingent life requires articulation, giving it recognition and the *other* autonomy. I conclude with a citation from Rubén Gallego concerning Tamara Cheremnova who had cerebral palsy and was maintained in a psychoneurological orphanage. His book attempts to tell a story from the standpoint of a "compensated debility." The intact "person in the head" is imprisoned by a weakened body. However, this body needs the hands of the other to extend it and provide a reach to the world:

> Living without hands is not so hard if you have everything else. Everything else—my body—is even worse developed than my hand. The hands were the main objects. We can say that the main thing in a person is their head. You can even stop speaking. It is clear that the head cannot survive without hand. It does not matter if it's your own hands or someone else's. (Gallego 2018, 145.)

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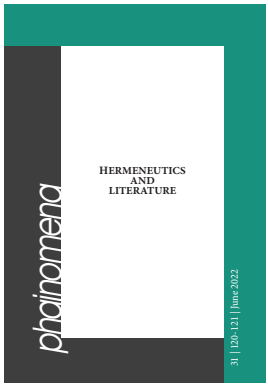

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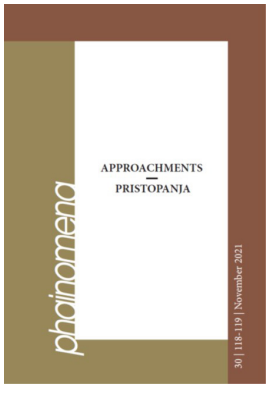

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