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DRAWING THE LOSS OF MOVEMENT: EMBODIMENT AND REPRESENTATION OF A PARKINSON'S PATIENT

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This paper is a reflective review on the experience of drawing my father during his last years with Parkinson's disease, as a framework to address the role of embodiment in drawing. More than a record of the body, drawing someone with Parkinson's disease is primarily to report a paradox: making visible the loss of movement and expression, but also the erosion of language and the disappearance of the other person's world. It is argued that drawing allows us to intimate this loss as an affect and an event, an emotion and a process, as the drawing act defies telling and incites a memorialising function of the trace.

As a projection of a moving body representing another body, drawing a Parkinson's patient triggers the experience of empathy as a shared representation, which enables us to perceive the other's experience within our own corporality. Empathy is addressed as part of the perceptual experience of drawing, but also as apperception: a co-apprehension of the other's emotion through his movements and expressions over time, blending direct observations and recalled images. As the enactment of a relationship, drawing is a coming together with the world, an "as-if-body-loop".

Introduction

Parkinson's disease is a neurological illness which progressively affects the ability to move and to speak. Although the progression happens in successive stages, symptoms may vary as the disease affects individuals differently. The deterioration of movement and speech has a direct impact on how the person's body constitutes space and the awareness of time, the sense of himself, but also his being-together-with others. Being a Parkinson's patient is an isolating experience, where the word 'loss' plays a vital role in a world that becomes narrower and narrower (Bruggen and Widdershoven, 2004).

The world of a Parkinson's patient is characterized by an existential paradox: life seems to be experienced as something motionless and, at the same time, unpredictable. This paradox is manifested in the person's corporality: the body may freeze and be unable to move, or it may function independently of the person's intentions in a sudden and uncontrollable movement. The feeling of being separated from the body, as something that can be presumed lost, defines the patient's awareness of himself: "to the Parkinson's patient the body is first something one is, then something one has, and finally something one no longer has" (ibid., p. 292). These somatic states also reflect the most intimate awareness of our own body. We experience the world as embodied, but we also conceive of ourselves and our bodies as separate entities, as if we are at one and the same time our bodies and not our bodies (Blocker, 2004, p.7).

How can drawing be used to enter the private perceptual world of a Parkinson's patient? What can it reveal of our awareness of that same world? I will address these questions through a series of drawings I made by observing my father during his last years with Parkinson's disease. These drawings were mainly made during my visits to him, over a period of eight years. They did not begin with a sense of a problem or as an aesthetic reconstruction of an intimate experience. Instead, they were led by the uneasiness of the situation, a way of passing the time in the absence of gestures and language. They belong to that category that Jacques Rancière named "naked images," a notion to which I will return later. Other drawings, made as memory exercises and gestural reenactments, appeared afterwards as a reflective response to this first set of drawings. These last drawings were made as deferred actions, as when an experience is recoded retroactively by a subsequent event: hand performances reenacting my father's gestures and clinical tests for tremor diagnosis of Parkinson's patients, memory drawings of his bed and situated dialogues with my mother, who accompanied him throughout his illness.

In this paper, I intend to explore the empathic mechanisms that allow us to embody the loss of the other in perceptual drawing. Instead of suspending the difference between self-experience and other-experience, drawing my father's motionless body takes the asymmetry in this relationship as a fundamental factor of empathy (cf. Zahabi, 2014, p. 138). This embodied approach to perceptual drawing can be described as a way of being in the game, of being caught up in and by the game, where strategies are not pre-determined, but emerge from a recurrent sensorimotor pattern that enables gesture to react and re-enact the content of representation.



FIGURE 1: UNTITLED, 2013. PENCIL, INDIAN INK AND RED MARKER ON NOTEBOOK. SITUATED DIALOGUE AROUND A DRAWING, SEPTEMBER 2018.

Drawing, Embodiment and Knowledge

Embodiment offers a new paradigm for considering the visual representation of bodies. When we draw, we trigger a unique form of intentionality directed at the experience of others, an embodied way of knowing them through their physicality and bodily expressions, even when their gestures and expressions stand in the threshold of stillness. Nonetheless, while many things unite us around the need of an embodied paradigm for drawing research, other things can divide us, depending on the angle by which we question the role of the body in the process of knowing through drawing. Like many other methodological lenses coming from cognitive sciences, embodiment can easily become a neuromyth in drawing research. What it means as a live performance act is very different from what it means in a memory drawing or in a situation of intimate observation, as if each type of drawing required a different awareness of the draughtsman's body, its sense of temporality, its possibilities and limitations. A fundamental aspect of the embodied approach to drawing is the recognition of the role of sensory-motor processes and emotions in the act of knowing. So, we could begin with an intertwined question which we, probably, have all asked at a given moment and for different reasons: How drawing shapes and is shaped by our emotions? How do we connect with the world of others through the act of drawing?

It is generally accepted that drawing is a physical and conceptual space where we can actually play with our thoughts outside our mind. The nature of this play – and of the thoughts being played – is nonetheless frequently bypassed for several reasons. One of those reasons can be explained by the

ubiquity of a referential fallacy in the way the word drawing is embedded in our language. This fallacy consists of confusing the object with its representations, assuming that the meaning of drawing has something to do with the object it depicts or the idea it stands for. The power of this fallacy is reflected in the emphasis we give to the content of representation or mark making, more than to the relational aspects surrounding drawing practice. Another reason is that when the process of knowledge is generally defined, people tend to associate it with the building of true descriptions and rational explanations, mostly in propositional forms, for how things work in the physical, social and cultural worlds (Johnson, 2011, p. 142). Knowing and feeling are different words in the dictionary, so they should stand for different acts of the mind. Knowledge is usually seen as a shared construction that allows us to distinguish something in the world – in Portuguese, the word for knowledge (*conhecimento*) literally means a common or shared understanding. Emotion, in contrast, seems to evoke an intimate and subjective response to an event, an individual experience that is circumstance-dependent and cannot directly become your experience.

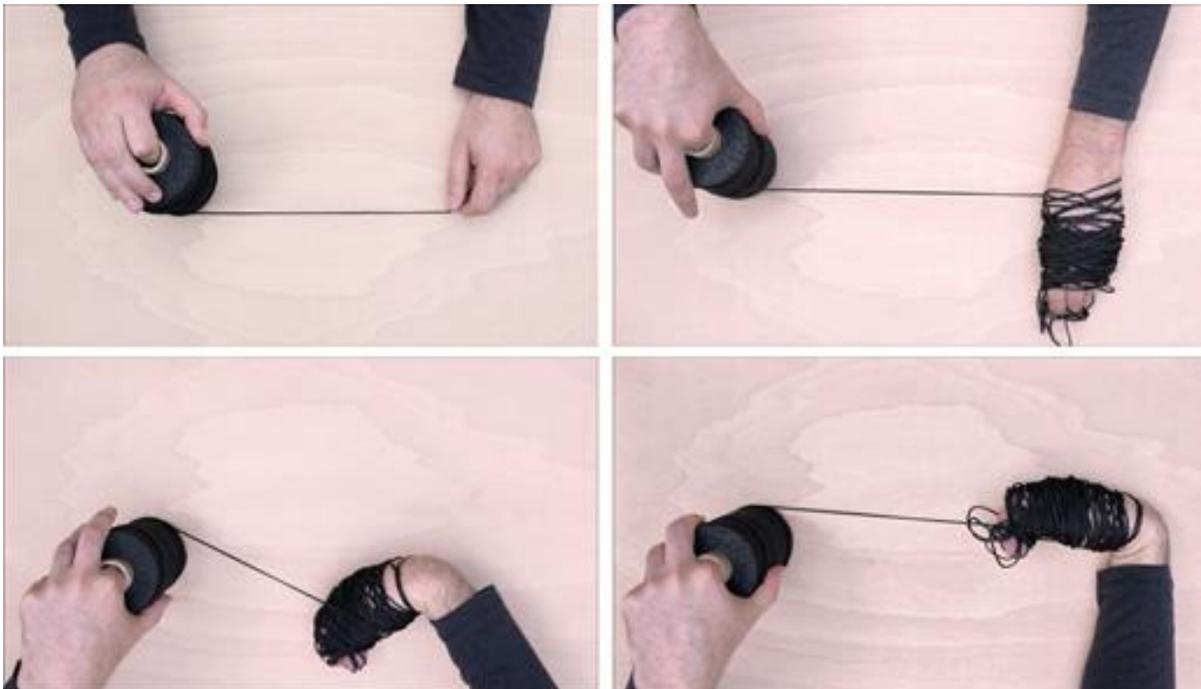


FIGURE 2: HAND PERFORMANCE (“THE VISIT”), 2019. BLACK NYLON THREAD.

Each one of these two statements is, of course, a misconception. Reality is much more complex. It is true that, when we draw, we think in propositional (descriptive) and analogue (depictive) systems, using ‘language-like’ or ‘picture-like’ representational strategies (Fish, 2004, p. 165). We are constantly playing with mirror-images and maps, pictorial information and diagrams, to address the complexity of the world as drawing. Nevertheless, this interaction is just part of the equation. It is also true that knowing and feeling are different states. However, as has been widely demonstrated (Damasio, 2000), there are overlapping areas between the process of reasoning and feeling, as there are between propositions and analogies, maps and mirrors. These are the overlapping areas that I have tried to address with the drawings of my father’s body. Bodies – and this is something that we all experience in our daily interactions – are not passive exhibitors of visual, auditory or tactile imagery. We see the content of representation as a re-enactment of our own experience as bodies. Every mark is in itself a projection of

the draughtsman's body, and this is particularly evident in the representation of other bodies (Rosand, 2000, p. 16). This implies that although drawing shares with images some of their properties, it is usually closest to dramaturgy than to the realm of pictures. Seeing a drawing is not the same as contemplating a picture. Drawing is an image-act that transforms the act of seeing into an embodied simulation of the gestures that produce it. Seeing a trace is re-inscribing it as an inner movement; we infer the deeper motivations of the trace from what our own motivations would be if we had done it ourselves.



FIGURE 3: THE ISLAND (MEMORY DRAWING), 2018. POWDER GRAPHITE, PENCIL AND WATERCOLOR ON PAPER, 52 X 65 CM.

When we draw, we are not just acting out an image, a perception or an idea. We are responding to the world. We are coming together with the world. This movement towards the world is, first of all, an emotional experience. But what is experienced cannot be transferred whole as such to someone else. There is something that is irretrievably lost. My experience cannot directly become your experience, as Paul Ricoeur (1976, p. 16) argued:

An event belonging to one stream of consciousness cannot be transferred as such into another stream of consciousness. Yet, nevertheless, something passes from me to you. Something is transferred from one sphere of life to another. This something is not the experience as experienced, but its meaning. Here is the miracle. The experience as experienced, as lived, remains private, but its sense, its meaning, becomes public.

What are emotions in this process? They are responses in the body and in the mind to deliver a solution and make us act. That is why emotions can never be defined as a state of pure passivity. It is through them that we can transform the world, in the condition that they transform themselves in thoughts and actions (Didi-Huberman, 2013, p. 39).



FIGURE 4: UNTITLED (NOTEBOOK 23.12.2011), 2011. PENCIL AND RED MARKER ON PAPER.

Drawing as Relation

For eight years, I drew my father several times every month. He died in May 2016, sixteen years after the first symptoms of Parkinson's disease. The involuntary tremors gradually became a state of muscular stiffness. The shaking palsy of the beginning of the disease gave way to an almost absolute immobility in the last years, confining him to bed for long periods, dependent on the care that my mother and others provided. In February 2006 he went into respiratory failure, which led to a definitive tracheotomy. From this moment on, he lost the ability to speak. Language is a skin: we rub it against each other, as if we have words instead of fingers. With the loss of his voice, my father lost the fingertips of his words — the ability of language to touch and connect with other people.

I started to draw him in an increasingly systematic way two years after the tracheotomy, accompanying the effects that Parkinson's disease had in his body. I had never drawn him before that. I think it was the lack of language and the uneasiness provoked by its silence that triggered this urge. Each visit was marked by the duration of drawings and the stillness imposed on us by the impossibility of language. The absence of language shaped the mode of drawing: not a sketch or a detailed illustration, but an indirect voice, a substitute voice that welcomes the voice of others. In the representation of someone we love, drawing quickly becomes an act of presence, a way of coming together. Drawing became the enactment of a relation, the pleasure of a relation as Jean-Luc Nancy pointed out (2013, p. 67):

Relation is not exactly transitive – it is transitivity, transit, transport ... it is the effect of one subject toward another, with its reciprocal necessity, and it thus involves the transport between them of some thing, force, or form that affects them both and modifies them both.

In the pleasure of relation, we gain consciousness of ourselves in the ability to affect and be affected through drawing. Relation suggests transformation, displacement or alteration of form. For Jean-Luc Nancy, the draughtsman experiences himself as other, an alterity or alteration. At the same time, when we draw, we create modes of interaction that humanise us in the eyes of those observed, as the illustrator and ethnographer Manuel João Ramos demonstrated (2004, p. 137). Both – observer and observed, draughtsman and portrayed – arrive at the image at the same time as it is made. We become suspended in a mirror relationship with one another. Sometimes, though, I was not sure if my father recognised me while I was drawing him. His eyes seemed detached from the outside images. Like other patients with Parkinson's disease, he suffered from violent hallucinations in the beginning, as a side effect of Parkinson's medication. Language was the only way we could access these images. But language failed. The states of absorption, even when he was awake, seemed deeper and deeper. "The gaze that cannot be returned is not only the most painful act of looking," as Deanna Petherbridge noticed, "but in many ways the most difficult to render as an affective exchange" (2010, p. 378).

There is an urgency in drawing motionless things that I had never realised before. Not the urgency we feel when images are moving and bodies run from one place to the other, but the urgency of things that can fade without warning, collapse without leaving their place, making our vision more intense and aware of small contingencies. Every representation is, in its most intimate reasons, the fear of a loss or the testimony of a disappearance. In drawing, a deep relationship seems to connect this mimetic impulse with memorialization. More than a play with appearances, mimesis – from the Greek mimeisthai – suggests that when we represent someone, we act like him, we call up his presence materially, in an indexical, rather than iconic, relation of similarity (Marks, 2000, p. 262). John Berger acknowledged just that when he described the urge of drawing as an attempt to save likeness, just like a lifesaver puts all his effort into saving a life, as if the intensity of seeing (and swimming) is triggered not by the object of desire, but by an imminent loss (2005, p. 68). As an embodied relationship, mimesis is a form of representation based on a material contact with the world and bound to a particular moment. Within that moment lies all the previous experience of seeing and being-with. This is how – Berger reinforced – the act of drawing contradicts the process of disappearance and loss: by replacing it with a simultaneity of moments (p. 71).

Coming together with the world is never a simple task and involves different ways of embodiment and disembodiment; of connecting or disconnecting the power of showing and signifying through drawing. In 'The Future of Images', the French philosopher Jacques Rancière proposed that images can be understood as operations according to their relationship with the world: naked images, ostensive images and metamorphic images (2007, p. 22). Naked images are those that do not constitute art. What they show us rejects the ambiguity of appearances and the rhetoric of exegesis. They are traces of a brute encounter with history or testimonies of an event that cannot be presented in any other way. Like naked images, ostensive images also testify and witness reality in its brute appearance but reconfigure its sheer presence as art. Metamorphic images are rearrangements of existing images that play with the ambiguity of similarities and the instability of dissimilarities to disturb or join the economic and social flow of images. If the work of art is to play with the ambiguity of appearances, then these drawings are

naked in the sense of a testimony by which representation seeks to embody the reality of the encounter in its most raw state. Naked drawings are an attestation of presence, more than a metamorphic transformation of reality.



FIGURE 5A: UNTITLED (NOTEBOOK 12.09.2014), 2014. PEN ON PAPER | FIGURE 5B: UNTITLED (NOTEBOOK 10.04.2016), 2016. PEN ON PAPER.

Drawing and the Memory of the Body

Each visit gradually became similar to the previous ones. Because I drew my father so many times, drawings were also repeating themselves months or years apart [Fig. 5]. The same strokes, the same outline to depict the mouth opened by the involuntary contraction of the muscles, the tubes that fed and breathed him, the same angles imposed by the position of the bed in the room, the same duration. Drawing became the arena for the inadequacy between the expectations created by previous drawings and the actual perception of my father's body in each visit. As an extension of seeing, drawing is related to hunting and dreaming; it is driven by the sense of possession; it responds to expectations and fears. Like seeing, drawing interferes with what is seen and alters the one seeing. It is as if the gesture of drawing could trigger a continuous circuit in which recalled images and current perceptions are mutually transformed, like a bicycle chain moving between two gears, allowing me to perceive the unnoticeable movements of my father's body. Such apperceptions, Shaun Gallagher argues (2017, p. 162) are involved in all perception:

just as in the perception of physical objects we do not have a direct vision of all sides of the object but, as Husserl explains, we apperceive the sides of the object that are not visible so that in effect we perceive the object as a whole, so we may also visually perceive the bodily gestures and expressions of the other person and likewise apperceive the non-appearing aspects of emotion.

Most decisions that we make while drawing require an interaction between perception and apperception: what current images show as being now and what recalled images show as something that we have seen before. But drawing also requires the anticipation of what will follow, and the process of imagination necessary to anticipate consequences depends on the memories of the past, as the neuroscientist Antonio Damasio demonstrated (2018, p. 65). Recalled images are an essential piece in the construction of narratives, our way of making sense of an arbitrary chain of events [Fig. 3]. Mentally, the order by which we introduce objects and events into a narrative – and my father’s body was for me a narrative – is decisive for how we store it in our memory. Many things that we memorise do not concern the past, but are a way of anticipating a future. The same happens in drawing. But drawing is not just about visual memory. There is a memory in our gestures when we draw which has nothing to do with the memory of images. It is closer to the capacity of a chess player to memorise the hand movements that connect the pieces in the board, more than the individual position of each piece, and use this memory to deal with new and unpredictable situations. Although the drawings made during my visits were mainly focused on my father’s body lying in bed, I feel my gestures were not iconic or image-based responses, but were cohesive movements. Cohesive gestures are recurrent movements that connect different parts of a situation that are thematically related but temporally separated (McNeill, 1992, p. 16). Gesture was a way of connecting and remembering. The drawings were forgotten in the drawers and in the notebooks, without any purpose or order. Only recently were they recovered as a deferred action and testimonies connecting a scattered sum of moments, like a narrative of naked images, in their raw witnessing of a relationship.

Drawing and Empathy

From a philosophical perspective, embodiment approaches in drawing can be seen as the extreme of a continuum, the other extreme being symbolic systems such as words, numbers and charts. The relation between embodied and symbolic systems has been visualised in various ways throughout history and contemporary drawing theory: as a continuum, as taxonomy, as a complex adaptive system. Nevertheless, it is undeniable that cognitive sciences have occupied, in the last years, a central role in the definition of conceptual, sensorial and emotional processes, which favours an embodied approach to representation. Even mathematical systems or symbolic devices such as Venn diagrams need an image-schema to make sense. Image-schemas are dynamics of reasoning structured in the body. They structure what we see, how we move and how we conceptualise experience, and are independent of visual perception. Cognitive sciences are today a battlefield where a new founding narrative of drawing is being formed, not without risks: a narrative that has occupied the space left vacant by the myth of Kora, daughter of Butades, and the fear of loss that led to the contour of her lover’s shadow. Embodiment is the new form of an old problem. However, embodiment cannot merely be an epistemological lens directed over our drawings or transformed into a curatorial category to frame performance-based drawings and create interesting possibilities for drawing-based collaborative practices. Embodiment is a state that is contingent upon the environment and the context of the body – an embodied drawing is a drawing that connects.



FIGURE 6A: UNTITLED (NOTEBOOK 17.03.2012), 2012. CHARCOAL AND RED CHALK ON PAPER | FIGURE 6B: UNTITLED (NOTEBOOK XX.XX.2012), 2012. INDIAN INK ON PAPER.

When we feel sympathy for a sick person, we recreate that person's pain to a certain degree internally (Damasio & Lenzen, 2005, p. 14). We connect. Not all feelings result from the body's reaction to external stimuli. Drawing my father was a mutual implication of my own body and his presence: a way of knowing him outside language; a way of connecting without language. His was not a quiet body waiting for some movement to imprint its mark; it was a body in motion, but in the threshold of what the eyes could perceive. Weight, flux, space and time are the perceived vectors that define the internal representation of the body. In my father's drawings, weight and space became the only vectors of what could be represented: no flux, no sense of time, just the duration of persistence. To a Parkinson's patient, the future shrinks to a here-and-now (Bruggen and Widdershoven, 2004, p. 293). Drawing became to me an act of being aware. It forced me to see, to search for patterns, to anticipate what would follow. But drawing was mostly an act of empathy – the sense of a body in loop. Empathy is like vision without distance: it is a metaphorical touch. If we bypass the fact that physiologically touch is a modality resulting from the combined information of haptic and nerve endings concerned with pressure, temperature, pain and movement, there is more to touch in drawing. It is a way to bring distant objects and people into proximity. When we touch or press something, our body assumes the shape of what is being touched or pressed. The Italian artist Giuseppe Penone used to describe this experience in his own drawing procedure as a notional reciprocity: "when the skin is touched, its surface adapts the shape of the contact point" (cit. in Tuma, 2004, p. 71). There is a sense of interaction and reciprocity in drawing a motionless body that is experienced as a metaphorical touch. The drawn marks are cultural indexes of individuality. Nonetheless, when my gesture seeks and reacts to the form of my father's body, like a mirror-touch, there is also a slight loss of identity, as the movement of my hand assumes the shape of his face, of his hands or the tubes that allow him to breathe.

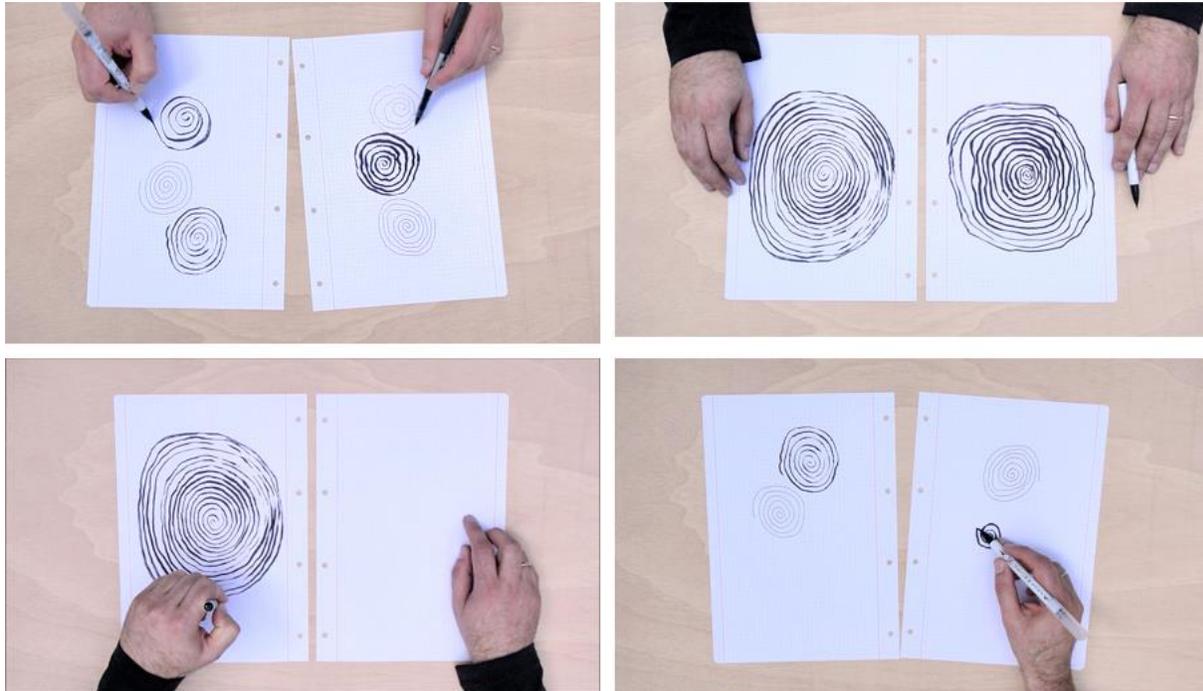


FIGURE 7: HAND PERFORMANCE (“THE VISIT”), 2019. PEN AND BRUSH ON SQUARED PAPER. DRAWINGS MADE AFTER THE ARCHIMEDES SPIRAL DIAGNOSIS TEST FOR TREMOR DISORDERS.

What is empathy in the act of drawing? We are all familiar with the mechanisms of internal imitation that occur in our personal relationships. They also happen in drawing processes. Observing, imagining or planning an action performed by someone else can generate, to some degree, the effort used to perform this same action (Blakemore & Frith, 2005, p. 261). This motor contagion is at the core of our internal imitation processes, of our capacity of anticipating, but also of the ability to perceive the underlying purposes and emotions on the basis of what our own intentions would be for that same action. When someone sees me pull back my arm as if I am going to throw a ball, she has in her brain a copy of what I am doing and that will help her understand my purpose, as an embodied simulation. Simulation is, generally, a negative word. To simulate is to try to become what one is not. But simulation is also a way of understanding beyond the limits of our own body and brain, a way of extending the body and the mind. In his research on the neuroscience of emotions, Antonio Damasio attempted to explain our corporeal involvement with pictures of things (not just bodies in motion) and to assess the emotional consequences of such involvement (2000). He emphasised the impossibility of feeling an emotion without a bodily involvement in what one observes: feelings like a rapid heartbeat can trigger an emotional response that makes us think and act in a different direction. His image of an “as-if-body-loop” refers to how the mind reacts in order to assume the same state it would have had if the observers of the actions and emotions of others were subject to the conditions they observed (Freedberg & Gallese, 2007, p. 201). Empathy is not just a way of bypassing the limits of our body. As a drawing experience, it is also a way of knowing, a process of intelligent inquiry and transformation of reality. While drawing, we transform observation into the imaginative knowledge of what it is like, which includes what is thought, felt, hoped for, willed, desired, encountered and done. Knowing through drawing is a matter of cultivating all these imaginative thoughts into a self-involving vision that allows us to transform perceptual experience into relational narratives. Documentarist Kutlug Ataman said it more clearly:

I look at people like buildings. Instead of walls and rooms, we have stories and experiences. As long as we can live these stories, express these stories, tell and retell these stories, then we can stand up the way a building stands (Honigman, 2004).



FIGURE 8: SITUATED DIALOGUE AROUND A DRAWING (UNTITLED, 2014. INDIAN INK AND RED MARKER ON NOTEBOOK), SEPTEMBER 2018

Aftermath

About 130 drawings portraying my father were made between 2008 and 2016 in notebooks. In 2018, I used some of them as triggers for a situated dialogue with my mother, to know her side of the experience of the disease, while taking care of my father [Fig. 8]. At the same time, the Portuguese Parliament was discussing the status of informal caregivers who, at the time, had no protection or recognition. Staging this dialogue around the drawings was a statement but mainly a speech-act of memorialisation. Drawing my father during those years was a way of making his affective state the intentional object of my awareness. Recovering those drawings was also an attempt to contradict and retrace the loss of movement of my father's body. As a consequence and an aftermath, several hand performances reenacting his gestures and the twisting contractions of his hands were staged for the Drawing Research Network Conference in 2019, on Embodied Drawing [Fig. 2 and Fig. 7]. In their constitutive differences, using a thread and a pen, the hand performances reenacted the Archimedes spiral drawing used as a clinical test to capture the frequency, amplitude and direction of a tremor in the diagnosis of Parkinson's disease. They were an attempt to embody the imperceptible movement behind the drawn marks. The awareness of gesture as a vulnerable movement that can be lost became evident: drawing the body "one no longer has" carries out the gesture of its own fragility. Drawing in this simulation mode was an eye-opener to my father's humanity within and beyond Parkinson's disease.

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