

Low vision as a phenomenological guideline

A baixa visão como diretriz fenomenológica

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Resumo:

"É em nós mesmos que encontramos a unidade da fenomenologia e seu verdadeiro sentido", diz Merleau-Ponty no prefácio da *Fenomenologia da percepção*. Amparada na obra do filósofo e, ao retornar a mim mesma como corpo-experiência efetiva de perceber, o objetivo deste texto é apresentar a baixa visão como diretriz fenomenológica de pesquisa para um caminho acadêmico na filosofia. Deparando-me com os limites do trabalho do teórico francês, tanto em termos fenomenológicos, quanto em abordagens sobre deficiência, indico um recente subcampo chamado de "fenomenologia crítica", integrado por filósofas da deficiência, entre outros.

Palavras-chave: baixa visão, corpo, deficiência, fenomenologia, percepção.

Abstract:

"It is in ourselves that we find the unity of phenomenology and its true meaning," says Merleau-Ponty in the preface to the *Phenomenology of Perception*. Based on the philosopher's work and, by returning to myself as a body-experience effective of perceiving, the objective of this text is to present low vision as a phenomenological research guideline for an academic path in philosophy. Facing the limits of the French theorist's work, both in phenomenological terms and in approaches to disability, I indicate a recent subfield called "critical phenomenology", made up of female philosophers of disability, among others. **Keywords:** low vision, body, disability, phenomenology, perception.



Verão 2024 I am a body with low vision tied to the world like other bodies. From my birth and as long as I am alive, this bond will never be untied, because it is the continuity of my experiences that express my existence through the core of meaning that is my body. My body and the world – not as a dichotomy, but as a totality – "shape" my experiences in an open outline. Starting from me – I: body-subject of my perceptions – my own way of perceiving activates the questions of the world and is activated by them in each of my perceptual experiences. My whole body is mobilized for me to type this text: I'm sitting in front of the notebook, in a way that I can see and hear it, type on it, move its position, close it, open it. I am involved entirely in this action, as in a melody that embraces me completely and transfers me to a unique place.

Since I was a baby, I have had a body with low vision: a situation that cannot be changed with the use of "ordinary glasses" or contact lenses; This characterizes me as a "visually impaired person". I learned – and continue to – deal with this body, which is me in interaction with mundane demands, because our activities and occupations change according to the choices we make and where we are situated. For example, all my life until I finished journalism school, my first graduation, at the age of 21, I wore glasses whose right eye lens is a 32-degree magnifying glass. I needed to glue my face to the paper to be able to read the texts that were already in enlarged font. I read the letters one by one, like a child being literate – it was the only way to read that I had found until then. A way that I didn't like because, as a child, I was laughed at. As he grew up, the laughter stopped, but the curious looks – many opening the question: "which planet did you come from?" –Remained. Not that I saw those scandalized looks: I "felt them in the air", like a mood of humor impregnated in the room. Not to mention the neck pain and scoliosis that I inherited from inadequate posture.

A few years later, as an undergraduate student in philosophy, my reading companion resigned, claiming that the amount of work I assigned him exceeded its limit: the large load of material to read did not fit the time that that magnifying glass needed to slide letter by letter. I had no option but to retire it in a drawer. I started to have help from readers, in order to take care of the subjects. Readers are people who read to visually impaired readers. I had several: classmates and graduate colleagues. They read the texts and I recorded them so that I could listen to them as many times as necessary. In fact, my glasses were never enough to perform all the reading tasks. Since I was little, I had people reading to me: first: at home; after: classmates at school; then: colleagues in journalism; Finally: fellows in philosophy. It was a great training for my hearing to have these people, in different periods, reading to me: the voices, the rhythms, the intonations – long "listening" exercises, since assimilating, with the ears, a content produced



VERÃO DE 2024 2024

with language to be assimilated with the eyes takes much longer, since it takes longer to hear the pronunciation of a word out loud, who read it to themselves. The effort to account for – listening – the linguistic specificities of writing requires greater concentration, as the eyes can choose an anchor point and remain there, while the ears are at the mercy of the sound of the environment, even if headphones are used.

Elaborating a "mind map" of a text heard is also very slow, since listening is necessarily sequential, while vision can be panoramic, as when leafing through a book to get a general idea of what it contains. Even more so if this text heard is spoken by someone who has a mechanical voice that makes you think: "if a can could speak, it would have this voice". Right now, facing my laptop, typing this text, I hear Max's metallic voice: my screen reader. Max, which came with this human name, is a software that, in interaction with my computer's operating system, pronounces, aloud, each character I type and, at the end of each word typed, it pronounces it in its entirety. With Max, I access the texts I write and read, listening, from character to character – including foreign words, which I do not know – to a line, paragraph or the entire document, according to what is convenient for each activity, be it study, work or leisure (cf. What Is A Screen Reader?, s/d).

I adopted Max at the time of doing the Philosophy Course Completion Work, so I could no longer organize myself with all those audio files that I recorded with my readers. I felt the need to interact with the texts: weaving notes, copying, pasting, cutting, marking passages – things impossible to be done in sound files, at least for me. Hearing the "machinic" sound of words through the voice of the computer, programmed to pronounce the peculiarities of the characters and punctuation, in a synthesized way, is completely different from hearing the vividness of a human voice, although some are not so lively (cf. What Is A Voice Synthesizer?, 2018). It is worth noting that the reading of philosophical texts, done with the ears, is considerably slower than texts from other areas: it is when they are read with the eyes. I listen to them over and over again until I understand their meaning and this understanding is not guaranteed, given the complexity of philosophical jargon. There are nights when I get noises in my ears from the fact that the machine voice, which reminds me of futuristic movies, has tormented me.

Added to Max: the reader software, I use a screen magnifier to help me in what I have not yet learned to do without the support of vision and to circumvent the "bad behavior" of the mechanical voice, which refuses to read many web pages, many pdf files and other formats (cf. Barbosa, undated). This is because most of the available digital content still needs to be set up to be readable by screen readers. In this way, in front of my face, turned to the left, because I can't see from the left eye and, with the right, of very low acuity, I also try to account for what the other does not see, three lines appear on



VERÃO DE 2024 2024

LOW VISION AS A PHENOMENOLOGICAL GUIDELINE. EK24064

the page, with three words on each line more or less. The focus imposed by the magnifier takes away my notion of the whole of the screen: I have to navigate through it in order to find what I want and, if I want to know the unfolding of each line, I have to move the mouse or the arrows to the left or right, scrolling through the words one by one. The process is similar to that with my magnifying glasses, with the difference that I am farther away from the notebook than from the printed ones – which my neck and spine thank in the midst of more bearable pain.

The way I open myself to the world, without a doubt, is guided by this disposition of my body: low vision that, in my understanding, creates a "style" of perception. This encounter between me and the world – perception – is only possible through my body, being, at the same time, touch, hearing, smell, taste, sight. Each sense constitutes "[...] a small world within the big one and it is because of its particularity that it is necessary to the whole and opens up to it" (Merleau-Ponty, 1999, p. 299). Immersed in the world by perception, the body lives: it feels and is sensitive to itself and to others; touchable, touching, touched, audible, hearing, heard, visible, seen, clairvoyant, even when it seems not to see or "see little": "to see less than others", like my body with low vision. A body that "sees less than others", that carries the ambiguity of moving between sight and blindness must be an expression of existence as old as humanity, although, for the majority, it seems, there are people who see and blind people, who are visually impaired.

My experiences have always shown me and show me a frightening lack of knowledge of people, in general, about disability experiences, especially about low vision. My readings also indicated to me that bodies with disabilities and their ways of being are left on the margins of academic subjects or are approached to emphasize experiences of bodies without disabilities. In the face of such findings, returning to myself as a body-experience of perceiving became a strategy of philosophical research, initially supported by the work *Phenomenology of perception* (1945), by the French philosopher Maurice Merleau-Ponty (1908-1961), which allowed me to recognize this body in which I live as "my own body", linked to its surroundings. At the same time that Merleau-Ponty makes a phenomenology of perception in the aforementioned work, he also makes a phenomenology of the body, without which low vision could not manifest itself. However, the philosopher's goal was not to deal with deficiencies specifically, although some are important in his understandings of the body.

So, with recommendations from colleagues from other areas until I was able to trace my own path, I went to research about a field called "Disability *Studies - Disability Studies* (Diniz, 2007). I came across anthropologists, sociologists, psychologists, educators... until philosophers appeared, finally, expounding their theories in the comprehensive field of study that disability constitutes. I discovered that disability



Verão de 2024 2024

LOW VISION AS A PHENOMENOLOGICAL GUIDELINE. EK24064

studies are also in philosophy in a specificity called "philosophy of disability". Talking about disability only makes sense because people have characteristics "categorized" as "disabilities". Thus, the account with which I began this chapter shows its pertinence: it is only possible to deal with disability by considering the bodies that live these experiences and their discourses always in a context.

Just as in philosophy, in general, we find works of a phenomenological nature, in the philosophy of disability, we can see them in a "subfield" called "phenomenology of disability". Merleau-Ponty's phenomenology is one of the foundations of this subfield. The fact is that neither Merleau-Ponty nor disability philosophers have addressed bodies with low vision in their approaches, according to my research so far. Having low vision is a possibility that is a little more than fifty years old, according to scholars on the subject (Amiralian, 2004). Before that, either the person saw, according to the norm (cf. Davis, 2006) doctor or was blind. Being a person with low vision, then, was the same as being blind, since the "visual residue" – as the vision of those with low vision is called in the medical and educational field – was discarded.

One of the first researchers to be concerned about the use of this "waste" was Natalie Barraga, a doctor of education, in the United States, in the 1960s. Barraga had a daughter with low vision, which led her to an interest in this area of study. Hers expression *low vision* (López, 2015) which, after some translations, was translated as "low vision" and, more recently, as "low vision". Here in Brazil, the concern driven by Barraga began in the following decade. However, the finding is that most of the studies on the subject are concentrated in the medical, pedagogical and technological areas (Amiralian, 2004). To date, scientific studies on visual impairment refer preferentially to people with congenital blindness, assuming that the understanding of the effects caused by blindness and the adjustment of blind people to the most varied situations includes issues pertinent to people with low vision: it is assumed that they are the same effects, to a "lesser degree", thus showing the ignorance about the use of visual residue (Amiralian, 2004), in addition to the little importance given to it as a component of the perceptive apparatus, which interacts with the other senses and their surroundings.

In research from the 1960s, there are reports of people with residual vision who were blindfolded to prevent what was considered "sample distortion". Until then, the diagnosis of visual impairment was made based on ophthalmological exams, so that these patients were referred to the teaching of Braille. However, they began to notice that children read Braille with their eyes and not with their fingers. This fact drew the attention of specialists to the use that these children made of visual residue, encouraging them to propose an educational diagnosis of visual impairment, which valued the way visual perception could be used in the learning process (Amiralian, 2004). The confirmation that children with the same



VERÃO DE 2024 2024

ophthalmologic measurement presented differences in the use of visual residue led to the need for a functional evaluation of vision.

In various ways of being, low vision does not manifest itself in a specific group of people; it does not appear in a territory delimited by social, economic, symbolic barriers. It is a phenomenon that manifests itself in people with different lifestyles, different habits, who go to different places and who think in different ways. What brings them together is the fact that they live in a world guided, for the most part, by those who are not visually impaired. This situation forces them to develop new ways of perceiving, to other particular pedagogies, techniques and strategies that allow them to open themselves to this world through their own bodies, which must be considered for their unique perceptual structure, not deducible from other bodies. So, we cannot deduce the structure of bodies with low vision from that of the majority - or an esteemed majority - of bodies: "those who see", in the literal sense of the word "see", we cannot deduce it from the bodies of blind people, remembering that, a few decades ago, blindness and low vision were still the "understanding" that was held of blindness since the beginning of "Western philosophy". We cannot deduce the structure of bodies with low vision or from other bodies with low vision – because people with the same visual acuity can have very different functionalities and experience disability in a very different way, according to the interaction of bodily, personal, environmental and social factors.

When we turn to philosophy, if low vision is a disability that has been conceptualized recently and – let's suppose – for this reason, absent from this discipline, what has been called "disability" has always been part of philosophical production in some way. However, let us think from the Modern Age: heir to the Cartesian conception of body-object, governed by "mechanistic laws" (Descartes, 2001), medicine "invented" this classification: "disability", to refer to blindness, deafness, spinal cord injuries, amputations and other ways of being. From a certain type of organic structure, framed as "normal", nineteenth-century medicine formed concepts and prescribed interventions, using physiological knowledge supported by the analysis of a supposed regular functioning of the organism, to look for where it deviated, what caused it disturbance, how it could be reestablished (Foucault, 1975; 1977).

From the intellectual eye that sees everything and corrects the deceptive vision of the corporeal mechanical eye, of which Descartes elaborated a physiology in the **The Dioptic** (2010), the gaze that was born with clinical medicine scrutinized the injured object to correct it. A blind eye, then, being blindness caused by some injury, needed to be corrected, treated, cured, just as it is done with diseases in general, which are manifestations of injuries. In fact, it was at this time (1893) that the classification currently known as ICD (International Statistical Classification of Diseases and Related Health Problems) was



Verão de 2024 2024

created (Buchalla & Laurentini, 2010). Linked to the idea of pathology, blindness was established as a particular form of disability. However, the "incurability" of most forms of blindness has subtracted them from the same effectiveness that medical action has for diseases that are usually temporary (Herzlich *apud* Martins, 2006, p. 81). Even so, blindness was established as a "pathological condition" that was called "visual impairment", born, according to the modern parameter, as a "deviation" in relation to the medical model of the body considered "normal".

This modern conception of disability, in which there was a causal relationship between injury and disability and an injured body appeared in opposition to a physiologically "normal" body, defined the "medical model of disability". This model remained intact until the 1960s, with the emergence of the "social model of disability" in the United States and the United Kingdom (Diniz, 2007). The result of the actions of activists with disabilities who fought for their rights, the new model postulated that disability was not an injury that was on a body, but a social disadvantage in the face of a society that did not respect human bodily variability. Injury and disability were "separated", the former being defined as the absence, partial or total, of a limb or organism or the detection of a defective bodily mechanism; and the second as a disadvantage or restriction of activity caused by contemporary social organization, which considers little or nothing those who have physical injuries and excludes them from the main activities of social life (Diniz, 2007).

The creators of this model were sociologists with physical disabilities resulting from spinal cord injury, for the most part, for whom the main impediments to achieving independence – a premise for these theorists – were social, architectural, and mobility barriers. If this were solved, the disability would no longer be a "problem" for them. These activists started from the assumption that all people with disabilities would be as potentially productive as people without disabilities, and it was only necessary, in order to produce, that the barriers that prevented the development of their skills be eliminated. However, soon the strategy was no longer to base the experience of disability in terms of specific injuries, such as physical ones, but to show that, despite the variety of injuries, there was a factor that united people with disabilities: the experience of oppression (DINIZ, 2007).

Unlike the medical model, which established a causal relationship between injury and disability and transformed the latter into an object of biomedical control, the social model resisted the thesis that the experience of oppression was a "natural" situation of an injured body. Thus, there was an inversion in the logic of the causality of disability between the medical and social models: for the former, disability resulted from injury; for the second, it was due to the oppressive social arrangements for people with injuries. For the medical model, injury led to disability; For the social, oppressive social systems led people



VERÃO DE 2024 2024

with injuries to experience disability. But on one point the models coincided: both agreed that the injury was the responsibility of biomedical care (Diniz, 2007).

By concentrating, the first, exclusively on a fragment of the body: the lesion; and the second, in the oppression exercised by society on people with disabilities, the medical and social models neglected the phenomenological experience of bodies with disabilities. This negligence began to be denounced in the 1980s, with the emergence of "Disability Studies" as the structuring of a new field of academic research in the United Kingdom: "Disability Studies" (*Disability Studies*) (DINIZ, 2007). The emergence of the body with lesions was a strong argument raised by feminist theorists who constituted the second generation of the social model in the 1990s and 2000s.

An agenda in the second generation of the social model, the body, as well as the individual who inhabits it and society, became part of the "health domains" established in a document published in 2001 by the World Health Organization (WHO): the International Classification of Functioning, Disability and Health (ICF). In this document, disability belongs to the health domains and is no longer explained as a consequence of diseases, as in the ICD, also under the responsibility of the WHO: "Disability: is characterized by the result of a complex relationship between an individual's health conditions and personal and external factors. It is an umbrella concept for injuries, activity limitations, or participation restrictions. It denotes the negative aspects of the interaction between the individual and contextual factors [...]" (Diniz, 2007, p. 49).

With the objective of describing information about the "conditions, functions and restrictions" of the human being with regard to health, in an organized and systematized way, the ICF is based on the integration of the social and medical models, in order to provide an integration between the biological, individual and social perspectives, resulting in a biopsychosocial model of disability. The biopsychosocial model brings together environmental factors, considering the barriers that people with disabilities face in their daily lives, responding to the social model of disability. At the same time, it considers the changes of a body with a disability, taking into account the precepts of the medical model. Above all, it goes beyond the mere description of the body or the environment, as it seeks to describe the interaction between them. The encounter between the different perspectives showed the insufficiency of the medical model to understand the experience of disability. On the other hand, the discussion provoked by the biopsychosocial model shook some of the pillars of the social model, such as the hypothesis that the body and its variations were neutral expressions of human diversity (Diniz, 2007).

According to the WHO recommends, the ICD and the ICF should complement each other, because, while the ICD offers the codification of an etiological model of diseases, the ICF allows the



VERÃO DE 2024 2024

evaluation of the "functionality" and "disability" resulting from the relationship between the state of health and the environment. "Functionality" refers to the individual's "capacity" to perform activities in the environment in which he or she finds himself: these are the "positive" aspects of the interaction between an individual's bodily "condition" with the environmental context, where the main focus is social participation. "Disability" refers to the limitation of activities or restrictions on participation: they are the "negative" aspects of the individual's interaction with the context (Who, 2008).

Disability is articulated with other social markers, forms different profiles of experience, according to health status, gender, ethnicity, education, socioeconomic condition, emotions, life history, culture and numerous personal factors and a multiple environment in conditions of accessibility, family structure, services, policies: factors acting as barriers or supports (Who 2008). More than quantifying diagnoses that reveal very little about individual needs, understanding the experience of disability, taking into account the way the person interacts with their surroundings and not from a "pathologizing" perspective, or from the lack of a function or part of the body, favors reflection on "real experiences" and allows thinking about practices that are more coherent with life in all its dimensions.

Over the past half-century, philosophers have begun to (re)think the meaning of the disability experience and intensify the study of how philosophical methodologies could be applied to this end. In accordance with what happened in the second generation of the social model of disability, in which feminist thinkers played a decisive role in questioning current theories, in philosophy, it was also feminists who moved decisively to the forefront of philosophical interest in disability, sometimes motivated by philosophical commitment to inclusion, sometimes by personal encounters with experiences of disability (Wendell, 1996, Kittay, 1999, Toombs, 1995 *apud* Reynolds and Silvers, 2017). Disability perspectives have become familiar in feminist approaches to topics such as ontology, epistemology, ethics, and political philosophy. In fact, the first international journal of philosophy of disability: *Journal of Philosophy of Disabilitymas launched in Oregon, in the United States,* in 2021.

Phenomenology, as it is a field that focuses on the lived experience of human beings, allows us to address singular experiences such as those of disability. Experiences of blindness (Reynolds, 2017), paraplegia (Abrans, 2014), diseases that lead to disability, such as multiple sclerosis (Toombs, 1995) and rheumatoid arthritis (Salamon, 2012) are part of a growing number of studies that point to phenomenology or a phenomenology of disability (Diedrich, 2001; Abrams, 2016); or a phenomenological model of disability (Martiny, 2015), which would be a third model after the medical and social ones. Whatever the denomination assigned, this topic focuses not on giving physical explanations, as in the medical model, nor on social prescriptions, as in the social model, to understand disability, but on first-person experiences of living with disabilities (Martiny, 2015; Carel, 2016). Phenomenologists of disability and



VERÃO DE 2024 2024

illness bring the appeal to pre-theoretical experience from the perspective of the first person, showing the importance that needs to be given to the voice of the body that experiences such experiences, very different from the scientific discourse in the third person, for which the body is only an object of analysis. We are not determined by anatomy, biology, or medicine, rather, we are in constant motion for our "launch" into the world: our experience of being in the world, each person, with powers and limitations.

The phenomenology of disability, as it has been developed, is added to a subfield that has gained notoriety in the last ten years called "critical phenomenology". The first journal dedicated to this critical turn, *Puncta: Journal of Critical Phenomenology*, was founded in 2018 by academics at the University of Oregon (USA). The Book: *50 concepts for a critical phenomenology* (2019), published a year later, became the main reference work of the nascent subfield. Some scholars claim that criticism modifies phenomenology to explicitly reorient it towards the goal of social transformation; others argue that phenomenology, from the beginning, was a project whose particular mode of attention to the world is itself critical (Lajoie, 2021).

For Lisa Guenther (2019), who presents the concept in *50 concepts for a critical phenomenology, critical phenomenology* goes beyond classical phenomenology, reflecting on social structures that make our experience of the world possible and meaningful, and by engaging in a material practice of "restructuring the world" in order to generate liberating possibilities of experience. As a transformative political practice, critical phenomenology must go beyond a description of oppression and develop concrete strategies to dismantle oppressive structures and create or amplify ways of being in the world. The ultimate goal of critical phenomenology is not only to interpret the world, but also to change it.

My intention to take low vision as a phenomenological guideline, in my understanding, is aligned with critical phenomenology because it seeks an understanding that shows low vision as a way of being in the world, not exclusively as an injured organ or as an abstraction that cannot be located and is sensitive in the body. The description of my experiences, even without a critical purpose, would already be critical. Because, when describing experiences of the body with low vision in the world, "adjustments" and "misadjustments" (Garland-Thomson, 2011) between body and world will become visible by the simple fact that they take place in a context that is social, historical and, therefore, privileges ways of being to the detriment of others.

The perceiving body – the subject of perception – moves towards the world around it, free of intellectual operations and prior to scientific explanations and philosophical analyses. This does not mean renouncing the knowledge elaborated by the sciences, philosophy, psychology, when dealing with perception. In fact, the dialogue with this knowledge is a strategy to prevent the experience of perception from being reduced to definitions that forget its lived foundation. According to Merleau-Ponty, from the



VERÃO DE 2024 2024

concrete act of perceiving, we can bridge the distance between the "I" that analyzes perception and the "I" that perceives, which, in fact, are the same, since it is not possible for us to interrupt this continuous act that is perception. In other words: we cannot stop perceiving to analyze perception, because our bodily presence in the world already means that we perceive something: "It is in ourselves that we find the unity of phenomenology and its true meaning", says Merleau-Ponty in the preface to the *Phenomenology of Perception* (1999, p. 2).

Low vision, perhaps, is a way for us to think about the phenomenological gaze not exclusively from sight, in its literal sense, but from a broadening of the horizon of visibility, as a process that does not necessarily pass through the eyes, but which implies the experience of perception as a possible condition of relationships mediated by the body. In this line, the gaze values other perceptive elements, as its field is also apprehended by the other senses: to look at an object is to come to inhabit it through the movement of perception, to interact with the world, touched by light, sound, odor, taste, texture, and in this way, to apprehend a knowledge that is hidden and does not manifest itself immediately (Merleau-Ponty, 1999, p. 122).

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Received: 08/2024 Approved: 09/2024

