

The Suffering Body in the Cultural Representations of Disability: The Anguish of Corporal Transgression

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Introduction

Grounded on a long ethnographic account of the experiences of blind people in Portugal within the Portuguese National Association of the Blind (ACAPO), my research has been devoted to exploring how blindness is culturally represented and experienced. On the one hand, the effort is to understand the processes through which the hegemonic cultural values towards blindness and disability are produced and reproduced. On the other hand, the effort is to explore how those dominant values relate with the experiences of blind people, those who know blindness and its implications in the flesh.

Blindness, Representation and Experience

Focusing on blindness I analytically embraced a condition that strikingly recollects the disabling dominant values in our society. Blindness figures among the impairments that are more vigorously enclosed within the ideas of tragedy and incapacity, ideas that are crucial to the social production of disability as a particular form of social oppression. Actually, the tragic perspectives socially associated with blindness constitute one of the reasons that led me to privilege the exploration of “blindness”, in spite of perspectives that claim for a political genealogy of categorical designations that discards “blindness” on behalf of “visual impairment” (for example, see Bolt, 2005). In an analysis that strongly addresses cultural representations with regard to the production of hegemony, blindness – rich as it is in historical and symbolic depictions in western culture (see Derrida, 1993) –

refers to a more precise collection of values and cultural conceptions than, for instance, visual impairment. Furthermore it is important to note that, contrary to blindness, visual impairment is a category that may lack readily analogous expressions in other languages.

My research is intellectually and politically engaged with the insights brought by the social model of disability. However, in this paper I would like to stress political and cultural dimensions, which are often approached with reluctance within Disability Studies, particularly within an “emancipatory disability research perspective” (Oliver, 1992: 111). By this I am stressing elements where the analysis of a disabling society crosses with questions related to phenomenology and embodied experience.

Certain experiences with a strong corporal dimension (such as the amputation of a limb, the loss of a sensorial ability or the onset of an impairment) carry strong implications for personal histories. Those events imply an ontological violence that goes further than the phenomenological and biological strains involved in the transformation of the body: the cultural descriptions available permeate that transformation and that violence. Phenomenological experience is enmeshed with the cultural representations of that experience. But, on the other hand, analytical attention to bodily experience blatantly de-authorises a naïve constructivism, which, while fighting the power of modern essentialist ideologies to derive social hierarchies from biological differences, has neglected, often to the limit, dimensions of existence where the lived body assumes irredeemable centrality. Grounded on a long ethnographic account of the experiences of blind people in Portugal, these questions, contending with ambivalent socio-political implications, will be summoned through the notion of the “anguish of corporal transgression”.

Before going further in the analysis of some elements where embodied experience and cultural representations of blindness are called to the fore, I shall provide a general overview of my research. My frame of analysis lays in the idea that blindness, as other impairments, is socially portrayed by contingent cultural constructions; hegemonic constructions that, rather than being sustained by the experiences of disabled people, are based on ancient symbolic heritages and echoes; on the biomedical modern episteme that invented disability as a pathological deviation from normality; and on the contemporary relations of power that sustain a disabling society. In my research the deconstruction of a medicalised modern conception that hegemonically pervades notions of blindness and disability is sought through three different perspectives:

1) A socio-political approach. Through this I address the alternative conceptions of disability brought by the social movements of disabled people. Particular attention is given to the social model of disability and to the oppositional perspective it offers by reconceptualising disability as a particular form of social oppression. With this perspective, in which the naturalisation of exclusion is strongly rejected, I wish to conflate theoretical work within the social model with an empirical analysis to allow me to explore the political endeavours of the organisations of disabled people in Portugal. I try to grasp the possibilities and constraints for a politicisation of disability in a country that in terms of its civil society is broadly characterised by a lack of social movements (Santos, 1994).

2) A sociocultural approach. Here I consider the Western history of blindness. Not only to grasp the meanings and symbolic echoes attached to blindness across time, but also to address the modern objectification of blindness as an impairment and, therefore, its naturalisation as a particular form of pathology under the “hegemony of normalcy” (Davis, 1995). Crucially, this western naturalisation of disability is also challenged in the ethnographic endeavour I undertook in 2005 in Mozambique, Eastern Africa. There, I explored cultural readings in which the Western categories about disability and disease give way to other aetiologies and meanings attached to corporal difference. In those apprehensions, the meaning of blindness (as the meaning of other perceived bodily differences) always depends on the social relations that are seen to be the underlying cause of it. The experiences of disease and impairment are invariably understood as the outcome of some kind of social conflict that is tackled through the resource to sorcery, activity which is taken to be the direct cause of damage to *somebody’s* integrity. So, in Mozambique, the meaning, implications and social perceptions of impairments crucially depends on a previous chain of events where sorcery and social relations are made decisive – social relations in which ghosts are an important part: they intervene in the world of the living, offering or withdrawing protection, acting in revenge or punishment. This ethnography reflected a more profound epistemic persuasion: the meaning of bodily difference always depends on the cultural mediations through which it becomes socially intelligible (Ingstad and Whyte, 1995; Butler, 1993). Cultural representations and forms of social organisation arise as decisive in defining possibilities and expectations for people with impairments. Therefore, in my perspective, this anthropological denaturalisation of disability through ethnographies in non-western settings appears as an important contribution to the political

perspectives that fight the dominance of modern medical models on behalf of a socio-political outlook.

3) An experiential approach. From this angle I confront the hegemonic values surrounding blindness with the personal experiences of blind people. This challenge was undertaken through a collection of life stories of blind people and through a longstanding ethnographic account of their daily experiences in Portugal. I will focus precisely on this last dimension: the relation between the experiences of blind people and the dominant cultural accounts of blindness.

The Personal Tragedy Narrative

In our societies the prevailing values about disability are largely not informed by disabled people's experiences and voices. But, in reverse, such values strongly inform those experiences in oppressive terms. The dominant historical and biomedical values converge with contemporary social dynamics to incarcerate the experience of disabled people in the ideas of tragedy and incapacity. Those constructions reiterate a 'personal tragedy theory' (Oliver, 1990) as the dominant socio-cultural grammar to address the experience of disability. I borrow from Michael Oliver the idea of a 'personal tragedy theory' to elect the *personal tragedy narrative* as a central concept (a cultural grand-narrative) to understand how disabled people's lives are continually confronted with dominant fatalist prejudices that enclose their experiences in disgrace and incapacity. I argue that in the cultural hegemonic representations about blindness this condition is strongly associated with the concepts of tragedy, misfortune and incapacity.

This conceptualisation of blindness is well expressed in our cultural artefacts. We can take, for example, the movie *Scent of a Woman* (1992), directed by Martin Brest (a remake of Dino Risi's *Profumo di donna* - from 1974). In this important display of the issue of blindness in the media, Al Pacino plays the role of Frank Slade, an ex-military soldier that had been blinded in an accidental explosion of a grenade. The central dialogue of the film occurs when Frank Slade is encountered preparing for his suicide. Charlie, the young man that assisted him in a trip to Boston, tries to stop him and says at a certain moment: "go on with your life". To this Frank Slade replies: "what life? I've got no life. I'm here in the darkness". The response yelled by Al Pacino can obviously convey the suffering felt by someone recently blinded in an accident. However, what I would rather emphasise is how this enunciation, in such an important evocation of blindness, largely reflects the terms by which this condition is socially

understood: a disgrace that challenges the value of life. These same ideas are present in the book *Blindness* (Saramago, 1995) by the Portuguese Nobel prize winning author, José Saramago. In that novel the sudden blindness of an entire population emerges as a rich metaphor to symbolize human disgrace, ignorance and alienation. That profusion of meanings and metaphors is brilliantly captured by one of Saramago's (1995: 204) characters: "blindness is also this: to live in a world where hope is gone". In fact, in the novel *Blindness*, the experiences of blind persons are virtually absent; I would say that they were replaced by the dominant cultural values and symbolic echoes involving this condition in the West.

In my perspective, this same replacement is what happens in contemporary social life, where the lives and reflections of disabled people are systematically subsumed by the dominant constructions of their experience. In blatant contrast with the dominant values, engagement with the experiences of disabled persons clearly shows how their lives and reflections tend to reject the notions of misfortune and incapacity. In fact, in my fieldwork with blind people, their positive views about blindness became quite evident, as their will to face the many obstacles posed to their self-accomplishment.

The Anguish of Corporal Transgression

As I started researching in the field of disability, I soon engaged with the perspectives brought about by the social model of disability. This model was created during the 1970s in the British context by the Union of the Physically Impaired Against Segregation (UPIAS), whose *Fundamental Principles of Disability* (1976) became a cornerstone document for the social movement and for Disability Studies. The insights they raised were later developed by Oliver (1990), constituting a precious theoretical corpus for my outlook of contemporary conditions of disablement. Contrary to some recent debates (see, for example, Shakespeare, 2006), my identification with the social model has never called for agonistic options in terms of my engagement with the different research approaches and theoretical sensitivities. This is so much so since I subscribe to most of the poststructuralist and feminist contributions to critical theory. Also, I have been interested in exploring how some personal and phenomenological dimensions of experience relate with the cultural representations of disability. However, in espousing those theoretical influences and research aims, I firmly disagree with the claim that they are irreconcilable with (or discard) the social model.

As such, in the same manner as I follow Judith Butler's (1993: xi) dismissal of a "prediscursive sex", and the consequent refusal of the sex/gender dichotomy, I believe that the distinction established by the social model between disability and impairment overlooks how impairment (its experiences and conceptions) is always permeated by particular social contexts; in short, that there is no prediscursive impairment and that even what counts as impairment is open to discussion. Moreover, as it might be trivial to say, the social model is not particularly interested in addressing the 'impairment effects' (Thomas, 1999), that is, the personal experiences of suffering and vulnerability more directly related to corporal conditions, and less dependent on social organisation.

However, in my opinion, those claims can only be seen to be in conflict with the social model if we take it to be what it is not. The social model is not a comprehensive theory of disability, but an oppositional political construction. It emerged to fight the hegemony of a 'medical' model that naturalises and individualises the conditions of exclusion endured by disabled people. In that sense I am comfortable with the pragmatic circumscription of the model offered by Oliver (2004: 11) that "the social model of disability is a practical tool, not a theory, an idea or a concept". In fact, it is important to understand, as Ernesto Laclau does (1996), that any project of emancipation is enmeshed in a particular history; therefore political action is always in contingent oppositional relation with identified structures of oppression. Through this perspective, the political empowerment envisaged by the social model cannot be discarded by criticisms that conspicuously fail to capture its obvious oppositional nature. Intellectual sophistication and attention to complexity cannot foreclose thought from engaging with oppositional political constructions, which are often dualistic. On the other hand:

it is important to resist that theoretical gesture of pathos in which exclusions are simply affirmed as sad necessities of signification (Butler, 1993: 53).

This implies that to use the social model is not to ignore approaches that explore the plurality of dimensions that mark disabled people's experiences.

While the most dramatic sociological insights have led us to the general identification of positive and empowering perspectives on blindness, as to the recognition of the disabling cultural values, those assertions can run the risk of erasing other experiential questions. I am referring particularly to experiences of suffering and privation more directly associated with the

corporal fact of blindness, that is: phenomenological experiences of emotional and bodily suffering that we fail to grasp from the perspective of social constructions and impediments.

This dimension of personal suffering, eminently corporal, hardly captured via exclusive socio-political explorations, I call the *anguish of corporal transgression*. The anguish of corporal transgression refers to the vulnerability in the existence given by a body that fails us, that transgresses our references in existence, our references in life. Understood as such, the anguish of corporal transgression permits us to consider dimensions of pain, suffering and existential anxiety where, against the conventional negligence, body and emotions acquire a noble status in social and anthropological reflections. In my research on blind people the centrality of the anguish of corporal transgression is allowed to capture two different phenomenological sets of experience: on one level, *experiences of personal suffering*, the experiences of blind persons who face in some moment of their lives a gradual or sudden loss of vision; on another level, *imaginative existential anxieties* towards impairment, the existential and corporal anxieties that result from the way blindness is construed through the perspective of bodies that can see. Trying to follow these paths, I became increasingly aware of the importance of recognising embodied experience as an important dimension. This is an emerging area of enquiry within the social sciences, traditionally uncomfortable in the exploration of such dimensions of experience.

Valuing the embodied dimension of human experience invites us to grasp the consequences of the fact that bodies are not only objectified with cultural meanings: they are also the ontological condition for “being in the world” (Heidegger 1962). It is through our bodies that we get access to the world and to others. Bodies feel pain, pleasure, endure sickness and violence, and, as Judith Butler (1993: xi) affirms, this cannot be demobilised as mere representation. So, I underline the words of Bryan Turner (1992: 41) when he sustains that:

To believe that the questions of representation are the only legitimate or interesting scientific questions is to adopt a position of idealism towards the body.

Returning to the anguish of corporal transgression to address it in the first dimension we mentioned – the experiences of blind persons – we are called to explore the experiences of suffering phenomenologically linked to blindness. I consider that this approach denies the idealism that could result from an exclusive socio-political analysis of what is implicated in the

experience of blindness. In this I follow Susan Wendell (1996: 42) in recognising that:

many disabled people's relationships to their bodies involve elements of struggle that perhaps can't be eliminated, perhaps not even mitigated by social arrangements.

In fact, as the life-histories and some experiences from my fieldwork showed, for *somebody* who can use vision, its loss can be received as a catastrophic event where the meaning of blindness and the meaning of life often intermingle, where the ideas of tragedy and emotional disruptions often arise. This ethnographic evidence is well expressed by John Swain and Sally French (2000: 573):

To become visually impaired, for instance, may be a personal tragedy for a sighted person whose life is based around being sighted, who lacks knowledge of the experiences of people with visual impairments, whose identity is founded on being sighted, and who has been subjected to the personal tragedy model of visual impairment.

This escape from a disembodied idealism is not a restatement of the personal tragedy narrative, far from it. In the stories and lives I approached, the sufferings more directly associated to the corporal fact of blindness are often absent. In fact, in the lives of persons that were born blind or that went blind through a slow descent of many years, as with some pathologies leading to blindness, the loss or disruption of references makes, existentially, little or no sense. The anguish of corporal transgression emerges essentially in the narratives of sudden, fast and unexpected loss of vision. It is in those stories that we find experiences of strong emotional distress stemming from questions that are not addressed by the social oppression perspective.

Even so, in those stories revealing the harsh suffering and mourning periods that may follow the loss of vision, we become familiar with the human ability for personal reconstruction. What is ironic is to perceive how the will to live in new terms, with new sensorial references in the world, has often to confront the fatalist values that enclose the experience of blindness. In that irony, what turns out to be tragic is this: someone having to live constrained by the values he strived to overcome. So, the focus on the transgression imposed by a body that fails and undermines references that 'organise' forms of 'being-in-the-world' is far from reasserting the naturalization of incapacity and misfortune. What the exploration of the experiential worlds relating to the corporal transgression does assert is the

density of experiences that are at once emotional, corporal and social. In my work this approach helped to apprehend and value how individuals struggle, endure, suffer or cope with experiences of radical disruption in their sensorial relation with the world. Therefore, in addressing embodied experience and correlating experiences of suffering I stand close to Arthur Kleinman (1992: 191) who affirms:

the challenge is to describe the processual elaboration of the undergoing, the enduring, the bearing of pain (or loss or other tribulation) in the vital flow of intersubjective engagements in a particular local world.

Addressing personal bodily experiences through the ideas of anguish and transgression implies, first of all the danger that the central sociological insights of social oppression and stigma will efface subjective experiences of suffering. As a concept, the anguish of corporal transgression sustains the centrality of bodily and emotional experiences for the meaning of life and for the references through which the world gains sense. This idea is operative in our trivial experiences and it gains increased evidence when addressing borderline experiences; experiences where disruptive events dramatically show how life can peril its foundations through the phenomenological body. In my work this was particularly obvious in the narratives of sudden blindness. In such cases, the strongest enunciation conveyed the confession of wishing to be dead or of an envisaged suicide.

So the anguish of corporal transgression captures and values subjective bodily experiences of loss and vulnerability as much as it sustains how our sense of life, of 'being-in-the-world', is gained _ and therefore may be lost _ through our bodily references in existence. However, if detached from the socio-political conditions, this socio-anthropological attention to the pitfalls of personal bodily experience could run the risk of confirming the dominant individualist perspectives on disability. Therefore, my support for a comprehensive perspective on the local 'worlds of experience' (via anguish of corporal transgression) is inseparable from a politically informed stance. The risk of losing touch with the socio-political conditions of oppression is well epitomised in Oliver's (1996: 5) contention that:

There is a danger in emphasising the personal at the expense of the political because most of the world still thinks of disability as an individual, intensely personal problem. And many of those who once made a good living espousing this view would be only too glad to come out of the woodwork and say that they were right all along.

Imagining Blindness, Representing Disability

In a different perspective – through *imaginative existential anxieties* towards impairment – I want to emphasise how the centrality given to the anguish of corporal transgression, with its emotional and corporal vectors, can help us to understand more about the dominant meanings socially inculcated in blindness.

From my research I want to argue that the tragedy associated with blindness owes significantly to the way people use their bodies to imagine: “how would it be if I was blind?”. This epistemological move, away from the modern consecration of a disembodied positive knowledge, is informed by the idea that:

there is no Cartesian dualistic person, with a mind separate from and independent of the body, sharing exactly the same transcendent reason with everyone else (Lakoff and Johnson, 1999: 5).

Rather, I want to consider bodies that think, situated bodies that produce knowledge and culture through emotions and visceral anxieties. Although historically neglected in social sciences, the significance given to embodied experience and embodied knowledge has gained relevance in recent times. In fact, an important contribution may be found in recent works that have emerged, strongly influenced by Maurice Merleau-Ponty’s (1962: 82) *Phenomenology of Perception*:

The body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment, to identify oneself with certain projects and to be continually committed to them.

Merleau-Ponty’s (1962) phenomenological stance constitutes a crucial call to argue for the embodied dimension of experience as for the idea of a “knowing body”:

In so far as, when I reflect on the essence of subjectivity, I found it bound up with that of the body and that of the world, and because the subject that I am, when taken concretely, is inseparable from this body and this world. The ontological world and body which we find at the core of the subject are not the world or body as idea, but on the one hand the world itself contracted into a comprehensive grasp, and on the other the body itself as a knowing body (p.82)

Following this line of thought, relevance should be given to authors like Thomas Csordas (1990, 1994a, 1994b), who brought to anthropology the

phenomenological heritage of Merleau-Ponty (1962), or to George Lakoff and Mark Johnson (1999), who argued the importance of body and emotions in the realm of cognition.

When I started my fieldwork among blind persons an interesting event took place. I was in a holiday camp working as a volunteer for the Portuguese National Association of the Blind. During the first night my sleep was disturbed by a nightmare. I woke with an intense sensation of angst: I dreamt that I had become blind. This episode is representative of my initial anxious response towards the spectre of blindness in my own body. From there on, due to an increasing familiarity with blind people and their life experiences, I gradually lost that initial preconception, revealed in the dream, about the terrible tragedy blindness would be. However, I gradually came to comprehend the crucial importance occupied by personal anxieties in the consecration of a personal tragedy theory as the dominant social narrative about blindness.

In fact, vision tends to be a central sense for someone who can use it: in the performance of activities and in the conception of the world. As a consequence, the corporal imagining of blindness from a body that lives visually tends to offer the idea of sensorial prison and incapacity. So, the anguish of corporal transgression is not only something experienced by someone who goes blind: that transgression is also perceived by means of the emphatic corporal projections through which blindness is imagined. I sustain that the importance assumed by the anguish of corporal transgression in the representations of blindness is not separable from a context where its symbolic historical heritages could not be more unfavourable and where the experiences and voices of disabled people are steadily silenced.

To defend the relevance of the anguish of corporal transgression is to defend the creative possibilities for meaning resulting from the emphatic imagination of a disruption. In fact, as Lakoff and Johnson (1999: 565) sustain, we constantly use imaginative projections to capture others' experiences:

A major function of the embodied mind is empathic. From birth we have the capacity to imitate others, to vividly imagine being another person, doing what that person does, experiencing what that person experiences. The capacity for imaginative projection is a vital cognitive faculty. Experientially, it is a form of "transcendence." Through it, one can experience something akin to "getting out of our bodies" _ yet it is very much a bodily

capacity...There is nothing mystical about it. It's what we do when we imitate. Yet this most common of experiences is a form of "transcendence", a form of being in the other.

The role assumed by the anxious imaginations of blindness emerged throughout research: in histories told to me by blind people and in the observation of the responses other people have when they somehow enter in contact with them: the "mixed encounters" that Erving Goffman (1963) talked about. Also, talking about my work with friends and colleagues I frequently heard people reflecting on blindness in terms that usually reflect their emotional relation with the spectre of that condition.

These imaginations not only produce personal anxieties towards blindness, they are also mobilized as a way to enter the reality of blind people. This emphatic identification with blindness is analogous to Lindsay French's (1994) reflections on the social responses produced towards the amputees she studied in a refugee camp in the Thai-Cambodia border. After analysing the stigmatisation produced by the values of Buddhism Theravada - particularly the ideas of karma and reincarnation - French (1994) points, in an instructive intersection of social and phenomenological approaches, to the visceral meanings enmeshed in a social reality emphatically marked by amputation as consequence of landmines:

We respond viscerally to the spectre of amputation: it challenges our own sense of bodily integrity, and conjures up the nightmares of our own dismemberment. We feel an instinctive sympathetic identification with the amputee by virtue of our own embodied being, but our identification frightens us; thus we are drawn toward and repelled by amputees simultaneously, both feeling and afraid to feel that we are (or could be) "just like them" (pp.73-74)

French wisely recalls, however, that the identification with the body of the other sustains the illusion that it is possible to empathically reach the experience of the other. This identification is inevitably erroneous and partial because we are always in a different structural position towards other bodily circumstances. I argue that this erroneous empathic identification is crucial to understand the detachment between the dominant representations of blindness and its embodied experiences, particularly in the centrality occupied by the 'nightmares of our own dismemberment'. As John Swain and Sally French (2000: 573) argue:

The problem for disabled people is that the tragedy model of disability and impairment is not only applied by non-disabled people to themselves, it is extrapolated and applied to disabled people.

The crucial question is that such a projective imagination of blindness allows an apprehension of the eventual impact of a sudden loss of vision, but fails to understand how someone's life can be reconstructed in new empowered terms without vision, fails to comprehend the adaptation allowed by a form of blindness that comes gradually through the course of several years, and fails to conceive the world without loss of someone that was born blind. What is produced is an empathic identification, partial and erroneous. The existential disruption it elicits and exports to the social meanings attached to blindness takes part in the re-production of its prevailing cultural representations in a way that fails to do justice to the complex experiences of blind persons. In that sense, the powerful enclosing of experience produced by the narrative of personal tragedy continually restates its premises.

Conclusion

In my view, the allegation that the anguish of corporal transgression is centred on the personal experiences of impairment in a psychological fashion would hardly be sustainable. While it is true that this concept is presented as a productive one to apprehend experiences of pain and suffering that sometimes are a part of the local worlds of disability, it also aims to address how hegemonic disabling values are reproduced from the personal visceral anxieties of the "able-bodied" towards disabled people. However, it is important to stress that the cultural role played by those anxieties is not understandable separately from their congruence with the dominant tragic views socially construed of disability, or without taking into account a historical reality in which disabled people's voices and experiences have been steadily silenced. Within this dynamic frame the narrative of personal tragedy keeps functioning as a hegemonic structure that guards the disabling status quo from urgent social transformations and from a wider politicisation of disabled people's lives.

Thus, I would argue that the cultural narratives through which disabled people's experiences are perceived appear strongly attached to the personal anxieties projected from an 'able-bodied world'. With its specificities, the analysis here undertaken over the representations of blindness retains a metonymic value to capture how the anguish of corporal transgression partakes in the way other impairments are lived and represented.

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