

Performance and disability: ways to health reinvention

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Abstract *This essay aims to make a dialogue between disability studies in its postmodern aspect, with the Anthropology of Performance from two paths: 1) discussing bodily influence on the meanings attributed to the experience of disability; 2) discussing how performance, with emphasis on sport, places the body in the light of sociability, generating a tension between new body norms and the reproduction of current models on disability and health. We conclude that the performance of people with disabilities can contribute to a review or reinvention of the concept of health from the construction of new identities and empowerment projects. Thus, disability is separated from the biological function/dysfunction and brings it closer to the human being's action capacity in the world by the sociability established in sport.*

Key words *Disability, Sports, Health*

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Introduction

Hegemonically, in the health and education literature, references about disability tend to be linked to the dialogue with special health needs, chronic health conditions, and the construction of identity with the recognition of the role of people with disabilities¹.

Goffman's interpretations² in studies on stigma and deviation contributed to the reflections on the place of social interactions in the construction of social identities. While he did not dedicate himself exclusively to reflecting on disability, the author considered that the social information issued by the disabled body could lead to the person's judgment as a discredited person. This conception can be internalized, and a deviant social identity can be assumed. The problem here is not in the body mark itself but in its assigned symbolic systems, producing meanings that signify experiences and shape the identity of people with disabilities².

Besides these studies, dialoguing with humanities, we highlight the Disability Studies pioneered in the United Kingdom in the 1970s. Strongly influenced by the social model, this disciplinary field centered the discussion on disability as a social phenomenon, identity unrelated to bodily injury (impairment)³. In this context, the first generation of social model theorists aimed to draw the attention to the social barriers that create inequalities by deviating from the biomedical approach on the disabled body, but still working with the injury/disability binarity, almost as a necessary contrast between the biological and social, as we found in the sex-gender parallel.

Internally in the field of Disability Studies, the feminist theory produces a critical aspect in the discussion on disability that will trigger the categories of gender and care as necessary to tension this field⁴. In short, the author points out that the deficiency in similarity to race and gender is a system of representation that marks bodies as subordinates.

Within the feminist studies on disability, in a Foucauldian lineage and Queer dialogue, the Crip⁵ Theory questions the able-bodiedness as one of the facets of ableism that dominates the interpretations about the disabled body⁶. Mello⁶ argues that ableism materializes in prejudiced attitudes, which produce hierarchies among the subjects, seeking to adapt their bodies to an ideal of beauty and functional capacity. This field of study provides a cultural understanding of disability, illuminating situations of inequality, and

discrimination as determinants for the oppression experienced by people with disabilities.

Both feminist studies on disability and the Crip Theory will debate disability by taking it to critical dialogue, activating the disabled body, seeking to accentuate corporeality, and refer to it in dialogue with other social markers.

This paper recognizes this background as a theoretical framework for relevant dialogues. It seeks to argue the experience of disability as a re-configuration of the body to arrive at a successful performance, and this is because our dialogue is based on the experience of adolescents with physical disabilities in the sociability of sports. The reflections can lead us to important notes for future studies about the difficulties of adolescents with disabilities. Tension with the new vital internal and external requirements characteristic of this life stage advocates an active body, ready for sociability. The valorization of the beautiful and prepared body for the performance reinforces an able-bodiedness ideal that can be activated by the adolescents when incorporating into the sport in a way that legitimizes the able-bodied norm.

We used the Performance Anthropology as a theoretical basis to dialogue with the health perspective, but in operation with the category of intersubjectivity. We considered that bodies with disabilities reach successful performances not only from the results of individual experiences, but can reach this pattern through experience that is configured from intersubjectivity. In other words, from the human being compared to other human beings.

Based on Schechner⁷, a good performance means achieving something within a standard that leads to success or excellence. This author argues that "performances affirm identities, bend time, reshape and adorn bodies, and tell stories"⁷(p.27).

Worth mentioning is that the articulation of an idea of performance, in the context of Performance Anthropology, the representations of the "successful, of doing something close to a standard" can be well questioned and discussed when we articulate performance with a discussion about experience, in a specific outline of the disabled body debated in feminist studies on disability. In this case, we cannot think about the body without considering networks of interdependence, imploding the myth of independence⁸, and not articulating the representation of an idea of overcoming to reach normative standards as a possible reinforcement of an able-bodiedness project.

Based on these considerations, we aim to explore the interlocution and tensions of studies on disability, in its postmodern aspect, with the Anthropology of Performance. Thus, we use the essay as a methodological design, here understood as a critical, exploratory search exercise about a theme or object of meditation, seeking a new way of looking at the subject⁹.

In this case, a critical essay does not fear to face dialogue between Feminist Disability Studies and the Anthropology of Performance, which is articulated by the concept of experience of the disabled body that is not triggered by the Anthropology of Performance. Thus, this essay argues that this contrast between a generic definition of experience, discoursing with comprehensive sociology, and its specification with the anchoring of experience in the disabled body, can prove to be instigating for the field of collective health, under the perspective of subjects building their bodies in sports.

The experience of the disabled body

We strategically resume the concept of experience to place it under a theoretical perspective that dialogues and operates with another strategic concept, that of intersubjectivity, anchored in the discussion about the body as a social construction.

The *Experience*, used here as a phenomenological term, denotes something subjectively significant that is consciously apprehended and cognitively constituted¹⁰ through reflection. Experience always occurs in the *world of life*, a sphere circumscribed by objects, people, and events where our actions are performed. Schutz¹¹ affirms that each individual builds his world. However, this construction does not arise out of the blue. The individual builds it from the relationships he establishes with other individuals. The world of life is the intersubjective world that precedes each life, and every interpretation about that world is based on a *stock of previous experiences*. Thus, “the world is not a world deprived of a single individual, but an intersubjective world [...] [However] we act not only in the world but also on the world”¹⁰(p.85). For this reason, the concept of experience is not to be confused with living, the particularity and intimacy of an individual restricted to his/herself, and neither that of perception. The possibility of shared construction underpins the experience, the intersubjective dialogue, apprehended by the subject in the

world, and which incorporates previous cultural background, the so-called stock of experience.

According to Schutz¹⁰, the *experience reserves* refer to the sedimentary knowledge inherited by individuals through their own experiences or their educators, whether they are of a practical or theoretical nature. Such reserves are anchored in the typicality of daily life, which refers to how the various social experiences conform based on a previously established model. This model dialogues with the *pertinence structures*, which are control measures established by individuals to organize and govern different social situations.

As our social actions in the world of life involve interactions between people, the body becomes central, mediating our relationship between personal and social identity, and is the locus of anchoring and dialogue with and of experiences. More than an object in which symbolic systems are inscribed, the body acts as our vehicle for being in the world, our means of communication¹². Mauss¹³ believes that the body is both the primary tool with which humans shape their world and the original substance shaping the human world. When using *body techniques*, subjects use their bodies to meet the tradition of a given context.

The valuations of experience and practice favored the body’s ascendancy as a reference in the social sciences. Evoking experience means valuing subjectivity and emotions as integral parts of investigative research processes. Rezende¹⁴ points out: “Embodiment is a methodological act that seeks to counter a conception of experience understood and dominated by discourse”(p.4).

Csordas¹⁵ dates from the early 1970s, and with increasing strength the late 1980s, as the phase in which the body assumed a living presence in the anthropological scene, and on the stage of interdisciplinary cultural studies. The embodiment paradigm brought the understanding that we are embodied social agents. Not only do we have a body, but are a body built from reflexivity, a body understood as corporeality, sensitivity, and objectivity.

With light shed on the experience, the body as an instrument of intentionality and intersubjectivity gains space, a physique endowed with agency, influential in social and cultural construction. Body and culture are then studied from a dialogical relationship. The body as a place where societal structures are inscribed, a vehicle through which society is built, and a circuit connecting individuals and society, as Rodrigues¹⁶ puts it: “society only finds existence in the underlying,

pulsating bodies of human beings: it is viscera, nerves, senses, neurons..."(p.177).

In the field of disability studies, the entry of postmodern approaches and feminist criticism in the 1990s and 2000s raised the banner of the experience of the disabled body, launching the second generation of the social model³. Some new axes of discussion open up.

The first is related to care. Topics such as dependence and interdependence were claimed in the disability agenda considering the status of people with severe conditions who require assistance with activities of daily living and social participation. The caregiver of a daughter with a disability, philosopher Eva Kittay¹⁷ brought up the issue of care beyond gender, setting dependence as part of the human condition.

The other axis refers to the disabled body. Without neglecting the social construction of disability, feminists advocated broadening their concept also to encompass chronic health conditions, a new approach to injury that would include not only medical descriptions but also the disabled body's experience in several circumstances, a phenomenology of injury, as recommended by Wendell¹⁸. Advocating the theory of both disability and injury in the field of Disability Studies, Thomas¹⁹ proposes that disability exists when environmental barriers impose the limitations experienced by people with injuries. The author argues that these limitations have psycho-emotional repercussions that must be addressed in disability studies. In this context, the injury must be considered not as a cause of disability, but as raw material that plays a central role in shaping the form and degree in which the limitation occurs.

These guidelines, until then, were neglected by the social model, as it was believed that it would be possible to develop the productive capacities of people with disabilities from the removal of social barriers. It was also thought that the narratives about the disabled body's experiences should remain private so as not to focus on the injury and undermine the claims that the disability was social and not individual.

Debating still the issue of the disabled body is, more recently, the Crip⁵ Theory. Just like the queer theory that questions the regulatory norms that establish "compulsory heteronormativity"²⁰, the Crip Theory is based on the poststructuralist approach and seeks a critical analytical position regarding the mandatory capacity of the able body and the materiality of the disabled body as inferior.

The feminist criticism and the new generation of theorists on disability must be understood as a process of expansion and reinvigoration of the social model³. The arguments demanded a look at the disabled body as an object of social action, a receptacle for the inscription of stigmatizing cultural symbols, but also as a producer of agency, place of experience, vehicle and engine for establishing new meanings and self-construction. At the same time, they highlighted the idea of interdependence as the basis of human experience, that is, we are all interdependent, breaking with the mystique of independence as a fracture between those with and those without disabilities.

In line with this argument, Hughes and Paterson²¹ propose an articulation for studies on disability, in which non-dualistic theoretical perspectives providing a cultural discussion and disability-related social processes, and a phenomenological approach for understanding the experience from the disabled body is valued.

Articulating experience and performance

An embodied understanding of disability experience may be possible through the Anthropology of Performance. Schechner and McNamara (1982 apud Ligiéro²², p.10) conceptualize performance as a "way of behaving, an approach to experience; it is playful exercise, sport, aesthetics, popular entertainment, experimental theater, and much more". It is the expression of body-mediated meanings, helping people to cope with difficult transitions, ambivalent relationships that question, exceed, or violate the norms of daily life, namely, the *social dramas*.

In the Anthropology of Performance, the body paradigm and embodiment contribute to a discussion that aims to understand the possibility of phenomenological transformation at the most profound body level, adding the emotional, rational, and bodily aspects of the experience²³.

We should briefly describe the social drama phases described by Turner²⁴ in order to understand how the Anthropology of Performance can dialogue with the experience of disability, as follows: *1 rupture*: a situation that threatens the stability of a social unit (family, community, nation) occurs; *2 crisis and crisis escalation*: the affected subjects/actors act and activate their support networks, and the crisis is an expansion of the rupture that has become open to the public; *3 reparative action*: the mobilization of the subjects/actors involved in the search for solutions

and conciliation efforts. It is the moment of reflexivity. The *strength*²⁵ – impulse or projection – achieved from a threshold experience drives the individual to action. Performance styles are now triggered by their ability to investigate the community's weaknesses, portray inherent conflicts, and suggest ways of redress; *4 outcome*: the efforts of the previous phase, when successful, involve rearrangement and redefinition of positions, establishing a harmonious relationship. The split occurs if the corrective action is unsuccessful.

Victor Turner²⁶, based on Dilthey, proposes an articulation between the Anthropology of Experience and the Anthropology of Performance by stating that “Experience incites expression, or communication, with others. We are social beings, and we mean what we learn from experience”²⁶(p.180). Painting, dance, sports are instruments of expression of meanings, putting them into circulation, a propositional, reflective, and expressive attitude, as pointed out by phenomenology.

The performances interrupt the life world's flow. Shifting the perspectives of actors from their normative roles causes them to adopt a reflexive attitude towards the *social structure*, enabling their revitalization. Turner points out that the social structure (daily reality) and the *anti-structure* (moments of social dramas) dialogue. At a given moment, the structure establishes the anti-structure; then, the anti-structure tends to contribute to the revitalization of the social structure itself²⁷. Understanding that we are bodies toward the world connected to it by the web of intentional threads we emit, the body participates in invigorating the social structure²⁸.

If we think of disability as an experience that can be dramatic depending on the socio-cultural context in which it occurs, the performance would be like an *action to repair* a conflictive disability experience. The dominant biomedical construction affirms that the disabled body can be considered an aberration, and is imperfect and abnormal. However, people with disabilities can use their bodies as a resource that allows them to explore new possibilities and opportunities. Limitations can be catalysts for new self-use ways.

We should clarify two criticisms that may arise from this line of argument. The possibility of exploring new capacities should not be mentioned here as a strategy for achieving independence but as a process of building “inter-subjective autonomy”²⁹ depending on the social relationship networks established by the person with a disability. The other point to be clarified

is the risk of the argument being used as a perpetuator of a disability management stereotype related to narratives of overcoming limits. On the other hand, we wish to emphasize the internal repercussions of a successful interaction, such as, for example, empowerment and the construction of identity.

The body is experienced differently when with impediments, requiring a creative re-embodiment³⁰. The condition of physical disability, for example, causes bodily attributes to appear to consciousness during an interaction. Due to greater assimilation of the perceived body, the form is continuously scrutinized by a diagnostic perspective, denouncing the unspoken question that asks, “what happened to you?”³¹.

People with physical disabilities must then negotiate two cultural conditions: invisibility as an active member in the public sphere and the elicited body hypervisibility. Performance allows finding another possibility for the inquisitive “ocularcentrism”, creating images that trigger visual contemplation, expanding the possibilities of symbols, spaces, and occupations of their injured bodies³¹.

One should dialogue here with the body image component that represents the Other's viewpoint, namely, the *value*³². Representing the subject's internalized social judgment that surrounds the physical attributes that characterize him, the value that people with disabilities assign to their image can be modified through performance thanks to its transforming potential of the adverse judgment associated with bodily injury.

Experimenting with new bodily practices through performance allows reframing disability through social interaction. Appropriating the *body erasure rituals* concept mentioned by Le Breton³² and extrapolating it to the physical disability condition in which body features are highlighted, performance could be employed as a ritual for erasing the body with a physical disability. The physical attributes are no longer the focus of interaction, a disability deconstructing process associated with the disability is established by questioning the rules that materialize and naturalize these bodies. The normality of the able body can thus be questioned.

Considering the deficiency in its bodily aspect and as a way of expressing capacities through interaction is to think of it as performance. Goffman³³ refers to the term as being role-playing, a type of ritual behavior of social actors in daily life. Examining the actor's experience through performance types, Turner²⁶ uses

the concept of performance associated with formative and transformative experiences, that is, sequences distinguishable from external events and internal reactions to them, triggering initiations in new ways of life. It shifts the gaze from the theater of everyday life brought by Goffman to the meta-theater of social life, believing that “the experience of the ordinary is also found in the outbreaks of the extraordinary”³⁴ (p.174).

Performing expressions, such as sports, contribute to the manifestation of an identity that is often dissociated from that of the daily world. For the disabled person, performing the body in other ways allows redefining oneself.

We want to shed light on the disruptive potential of sport as a mechanism for creating new standards for the disabled body. However, there is also a need to discuss this space as a reproducer of able body-related hegemonic norms, keep disability on the sidelines.

The disabled body as potency

We trigger Aristotle’s concepts³⁵ when speaking of the body as a potency. When dealing with the term *Being* in its various meanings, the philosopher conceptualizes *potency* as the source of change in something else. The philosopher defines *movement* as the realization of what is in potency. We assume the disabled body as a potency, a principle that originates changes, which is expressed through movements in different performing styles.

Considering performance as a way of becoming or making explicit the disabled body’s potency and a space for the exercise of intersubjectivity, we highlight *sport* as one of the possible ways for a successful performance of people with disabilities, a way of breaking the mechanical association between deficiency and disability.

Historically, the development of sports has been associated with assistance in the invention, testing, and consolidation of bodily skills that ensured food, shelter, and physical protection. Sports have played a vital role in establishing and maintaining social relationships and the cultural identity of the community³⁶, transcending their initial role as providers of material and physical needs. Sports today provide a view of how life can be lived when not consistently dominated by need. It is a generator of rules that transcend our conduct in the world of life. It is where, from the interactions, identity traits and also a place for expressing feelings are assumed. Sports allow

forging relationships that can mirror, sustain, or anticipate changes in sports and social life³⁶.

Sports are associated with hegemonic ideals of masculinity, physicality, and capacity development. This scenario is established as a useful space for debating the social reiteration of the superiority of the able body when compared to the disabled body³⁷.

Gender issues are involved in this process as they guide values associated with physical performance. Performance expressions can reproduce, challenge, or transcend the male-female dichotomy and the concepts associated with normality and abnormality³¹.

According to men with disabilities, participation in sport and body development, promote self-esteem and feelings of potency and capacity, offering them an opportunity to reaffirm their masculine values. On the other hand, bodybuilding does not fit into conventional femininity concepts. Women are seen as athletes in a wheelchair, and gender, in this case, is eradicated. The social category of an athlete and the meanings associated with the wheelchair transcend femininity. In this sense, the primacy of male sport-reinforced physicality assists more prominently supporting identity and the sense of belonging of men with disabilities in a context where body normality is compulsory. Disabled women engaged in sports must exercise to reaffirm their identity through other ways, such as feeling attractive from a fit body or being physically well to exercise their care activities³⁰.

Crediting success in sport to the ability to meet the standards of an able body reinforces what McRuer⁵ calls compulsory able-bodiedness, a term used to describe a cultural understanding that places the understanding of disability based on an idea of lack of imperfection. It is precisely the criticism of the materialization of bodies with disabilities as inferior, seeking to deconstruct the regulatory process of normalization that permeates the division between bodies based on the Crip Theory postulated by the author.

In sports, the discourse of overcoming to achieve performance close to disability-free bodies reinforces ableism, pressuring subjects to act in order to overcome limitations, who are extraordinary due to their ability to succeed despite their disabilities³⁷.

We wish to highlight the dialogue between sport and disability not only as a way to achieve a conventional representation of an able body, reinforcing an idea of compulsory able-bodiedness. Besides the notion of normality, sports

performance sheds light on disability concerning Canguilhem's norms^{38,39}. The author's conception that the subject's health pattern is characterized by his ability to create new norms can be extrapolated to the field of disability. Sports performance can be a creative activity polarized against what is decline and impotence, producing new rules for framing the disabled body in society.

A type of autonomy and sociability is established in which the body assumes the position of agency, movement, and control. In this case, the disabled body operates intersubjectively, exercising interdependence with the sports practice that develops the body as power, control, reinvention, recognition of values, and virtues. Worth mentioning is intersubjective autonomy, derived from the recognition discussed by Honneth²⁸ as a way of removing the possibility of associating autonomy with independence. In this context, attention is focused on feelings of self-confidence, self-respect, and self-esteem derived from recognition in social relationships. In the case of sporting performance, recognition helps in the social self-realization of people with disabilities.

Sport builds a dialogue between people with and without disabilities and criticizes the apparent bodily limits³¹. The body *hexis* involved in sport underpins a system of symbols that promote a new place for the physique and a reformulation of identity. The shape considered as deviation dissolves in the exercise of sports activity, which eases the feeling of being kept at a distance due to personal physical attributes, reinserting oneself in the symbolic field that gives meaning and value to social actions.

As catalyst for emotions, sports offer opportunities to experience emotional satisfaction associated with the exercise of physical capabilities⁴⁰. The creation of tensions uplifts feelings. Imaginary danger, fear, enthusiasm, sadness, and joy are produced and possibly resolved in the framework of amusements. Different states such as anguish and exaltation, agitation and peace of mind are boosted.

The interaction that occurs in sports performance authorizes the collective manifestation of intense feelings. It is sports as the support of what Simmel⁴¹ called *sociability*, pure, self-containing end association processes that forge an artificial world built by beings that wish to produce a pure interaction not unbalanced by any material tension.

Turner describes the experience of *communitas* as a feeling of group solidarity generated

during a ritual, and that can happen during the sport in which, when playing very well, each player feels in close contact with the others, a sense of "we are all together"²².

In contrast to the often hostile and discriminatory environment in the lifeworld, the group where the performance takes place can be considered as a place of belonging and sharing common interests: a place of *protected sociability*⁴². The group's subjective meaning stems from the sharing of classifications and relevance defining social roles, positions, and the status of each one. The use of a common relevance system leads to homogeneous self-classification by group members, allowing open and appreciative space to be built where new standards can be developed.

Final considerations

At the interface of the disabled body and performance, health, in general, should be reviewed or even reinvented, starting with the deconstruction of specific mechanical associations without being debated, such as injury-illness and deficiency-disability. A disabled body, in certain situations and conditions, can perform for specific purposes more successfully than a disability-free body. On the other hand, disability is not always an impediment to functionality, which can be resolved when we break free of idealizations or unique patterns to arrive at the concept of disability that includes a diversity of lifestyles and understanding it as a positive moral value.

Focusing on the subject's ability to act in the world of life through performance styles contributes to overcoming the naturalistic perspective on health, in which disabled bodies are reported as incidence rates and deviations from the statistical norm. This data is essential as a starting point for thinking about inclusion projects or assistance to adolescents with disabilities, but never as a point of arrival to compose a simple profile or a report on how the relationship of bodies with and without disabilities is configured.

Another vital aspect to highlight in the dialogue between performance and health, in general, is the shifting from the idea of normalization, in which the successful performance act would be a simple way for the acceptance and overcoming of disabled bodies or even for presentations to be achieved only for entertainment, or even for-profit purposes. Moreover, performance must not be reduced to an ableism product to obtain social acceptance of disabled bodies. In

this sense, the performance/sport/health/education overlays must be complexed. For adolescents with disabilities, experiences in a context of compulsory abled-bodiedness can trigger the non-critical ableist bias of sport, colonizing them in a pattern that restricts them and prevents the affirmation of the disability.

We want to shed light on the performance to be achieved by these bodies as a reflection of internal dimensions, such as empowerment proj-

ects, construction of personal identity, experience of pleasures, the establishment of corporate life, among others.

Finally, we point out that uncertainties, challenges, and powerlessness still traverse the discussion raised by us. However, if at least these aspects cause some uneasiness or discomfort regarding the topic, as health professionals, we can not only rethink actions that will continue the discussion but reinvent ourselves to gaze at other horizons.

Collaborations

TV Santos was responsible for the conception, design, and writing of the paper. MCN Moreira and R Gomes participated in the conception, design, and critical review.

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