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CONTRIBUTIONS FROM THE ETHICS OF ALTERITY TO THE DISABILITY STUDIES: A STATE OF ART[1]

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ABSTRACT. The advancement of national and international laws has contributed to reassuring the dignity and fundamental rights of people with disabilities. Even so, the effective sociocultural participation of these people is jeopardized by discriminatory barriers imposed across multiple spheres of society. Therefore, it is necessary to promote reflections about ‘normality culture’ and its consequences in situations of exclusion, oppression, and discrimination of people with disabilities. This study aimed to analyze the contemporary concept of disability in the light of Emmanuel Levinas’s philosophy, author responsible for criticizing Western philosophy affirming that the exclusion of alterity stems from it. To this end, a State of the Art analysis was done, and 12 papers, 11 master’s theses, and 4 doctoral dissertations were found. The works were classified by quantitative characteristics and were later analyzed in the light of Levinas’s major work, *Totalidade e infinito*, and the contemporary studies on disability, ethics, and responsibility. It was observed that the works had done critical analyses about governmental actions and interventions destined to people with disabilities, showing the insufficiency in ensuring fundamental rights of these people. We also identified the need to substitute conceptions that totalize and universalize the differences with perspectives that recognise the Other in its singularity. This article concludes that the Ethics of Alterity proposed by Levinas invites one to infinite commitment of the Self to the Other, who does not expect anything in return to the aid provided. Therefore, it is relevant to politics and the academic field as an ethical, theoretical, practical, and analytical principle to interpret questions relating to the field of disability studies.

Keywords: State of the art; disabled people; ethics of alterity.

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CONTRIBUIÇÕES DA ÉTICA DA ALTERIDADE PARA OS ESTUDOS DA DEFICIÊNCIA: UM ESTADO DA ARTE

RESUMO. O avanço de legislações nacionais e internacionais contribuiu para a reafirmação da dignidade e dos direitos fundamentais das pessoas com deficiência. Ainda assim, a efetiva participação sociocultural dessa população é prejudicada pelas barreiras discriminatórias impostas nos mais diversos âmbitos da sociedade. Faz-se necessário, portanto, promover reflexões sobre a 'cultura da normalidade', e sua consequente influência em situações de exclusão, opressão e discriminação dos sujeitos com deficiência. A presente pesquisa teve como objetivo analisar o conceito de deficiência na contemporaneidade sob a ótica da filosofia de Emmanuel Levinas, autor responsável por tecer críticas ao pensamento filosófico ocidental, principalmente às ações de exclusão e discriminação da alteridade dele decorrentes. Para tanto, utilizou-se o método do Estado da Arte, coletando-se 12 artigos, 11 dissertações e quatro teses. Os trabalhos foram categorizados de maneira quantitativo-descritiva e, posteriormente, analisados a partir da obra *Totalidade e infinito* e dos estudos contemporâneos sobre deficiência, ética e responsabilidade. Observou-se uma análise crítica dos trabalhos em relação às atuais ações e intervenções voltadas ao público com deficiência, denunciando sua insuficiência na garantia de direitos fundamentais. Constatou-se também a necessidade de substituição de concepções totalizantes e universalizantes das diferenças por perspectivas de reconhecimento do Outro e consideração da singularidade humana. Conclui-se que a Ética da Alteridade, proposta por Levinas, convida ao compromisso infinito do Mesmo para com o Outro, à ajuda sem espera de reciprocidade, fazendo-se, portanto, relevante nos campos político e acadêmico como princípio ético, teórico-prático e analítico para a interpretação de questões relativas à deficiência.

Palavras-chave: Estado da arte**;** pessoas com deficiência; ética da alteridade.

CONTRIBUCIONES DE LA ÉTICA DE LA ALTERIDAD A LOS ESTUDIOS DE DISCAPACIDAD: UN ESTADO DEL ARTE

RESUMEN. El avance de la legislación nacional e internacional ha contribuido a reafirmar la dignidad y los derechos fundamentales de las personas con discapacidad. Todavia, la participación sociocultural efectiva de esta población se ve obstaculizada por las barreras discriminatorias impuestas en los más diversos ámbitos de la sociedad. Por tanto, es necesario promover reflexiones sobre la 'cultura de la normalidad' dominante, y su consecuente influencia en situaciones de exclusión, opresión y discriminación de sujetos con discapacidad. Esta investigación tuvo como objetivo analizar el concepto de discapacidad en la época contemporánea desde la perspectiva filosófica de Emmanuel Levinas, autor responsable de criticar el pensamiento filosófico occidental, especialmente las acciones de exclusión y discriminación de la alteridad que de él resultan. Para ello se utilizó el método del estado del arte, recogiendo 12 artículos, 11 disertaciones y 4 tesis. Las obras fueron categorizadas de manera cuantitativo-descriptiva y posteriormente analizadas a partir de la obra *Totalidade e infinito* y estudios contemporáneos sobre discapacidad, ética y responsabilidad. Se observó un análisis crítico de las obras en relación a las acciones e intervenciones actuales dirigidas al público con discapacidad, denunciando su insuficiencia en la garantía de los derechos fundamentales. También se señaló la necesidad de reemplazar las concepciones totalizadoras y universalizadoras de las diferencias por perspectivas de reconocimiento del Otro y consideración de la singularidad humana. Se concluye que la Ética de la Alteridad, propuesta por Levinas, invita a la implicación del Mismo hacia el Otro, para ayudar sin esperar a la reciprocidad, volviéndose, por tanto, relevante en los campos político y académico como un enfoque ético, teórico-práctico y marco analítico para la interpretación de las cuestiones relacionadas con la discapacidad.

Palabras clave: Estado del arte; personas discapacitadas; ética de la alteridad.

Introduction

In response to the long history of exclusion, marginalization, and violence imposed to the wounded body, the Social Model of Disability was developed by and for people with disabilities, aiming, through theoretical propositions and political actions, to affirm disability as a lifestyle rather than a biological doom to failure (Diniz, 2007, Maior, 2017). The paradigm innovation proposed by the so-called ‘first generation’ of the social model was to hold society accountable for imposing barriers on people with disabilities, hindering their social participation through exclusion and discrimination (Gaudenzi & Ortega, 2016).

The social model was essential to denounce the oppression experienced by people with disabilities, as well as to reaffirm the need to secure their social, economic, civil, and political rights (Dhanda, 2008). The paradigm shift that this perspective proposed was adopted in different international legislations, such as the International Classification of Functioning, Disability, and Health (ICF) and the International Convention on the Rights of Persons with Disabilities (CRPD) – document that was signed and incorporated into Brazilian legislations. Such documents emphasize the need to affirm disability as a result of the interaction between a body with biological impairments (injury) and an unequal society that excludes the diversity of lifestyles (Santos, 2016b).

The progress achieved by the ICF and the CRPD notwithstanding, the reaffirmation of the rights of people with disabilities did not guarantee the elimination of discriminatory barriers and social marginalization imposed on this population. The advent of the social model's ‘second generation’ was essential to denounce deeper structures inherent to contemporary society and responsible for the existence of a ‘normality culture’ (ableism or *capacitismo*), which reifies individual autonomy, ignoring that not all people with disabilities desire or are able to achieve independence from others to live in society (Diniz, Barbosa & Santos, 2009).

Taking into consideration the demands for guarantees of fundamental rights and dignity, it is necessary to rethink not only the references, but also the relations established with people with disabilities in order to promote effective social inclusion. Based on such reflections, the present work aimed to contribute to the advancement of the current model of intelligibility of disability adopted by Human Sciences areas through the contributions of Emmanuel Levinas's philosophy, especially the ideas expressed in his major work: *Totalidade e infinito*.

Levinas (1993, 2015) yields a deep and scathing critique of modern philosophical thought which, due to its predilection for universality, would be responsible for supporting actions of exclusion and discrimination of the Other, operated by the suppression of difference and indifference towards it present in a totalizing tendency. According to this author, Western philosophy stems from an ontological conception in which Being – the absolute and autonomous Self – is the center and the measure of all things (Almeida, 2013). The consequence of this perspective is the carrying out of practices that completely disregard the Other and that, ultimately, represent attempts to impose dominion and power over alterity as well as blunt and silence its irreducible difference.

Alterity is the "[…] radical heterogeneity of the Other" (Levinas, 1980, p. 23), which cannot be transformed into a mere object of knowledge of the Self and establish relationships of identity with it since it constitutes an indisputable resistance to any type of domination, capture, or intelligibility. For it is infinite, the Other transcends any and all attempts by the Self to conceptualize and totalize, which Levinas calls the 'Same'.

Even though Levinas does not make a direct connection between his philosophy and the issues concerning disability, the alterity of people with disabilities is ignored and forgotten by current society, which, centered on an ontological perspective of being, values uniformity to the detriment of difference and refuses to take responsibility for the Other in the face-to-face encounter (Martinelli, 2015). Thus, the author states that ethics must be adopted as First Philosophy in order to operate a shift from the question of Being and of knowledge to *being-for-the-other* as a new foundation for thinking about humanity (Almeida, 2013), different from the Hobbesian social contract model (Carrara, 2010). Face-to-face ethics is the basis for this new foundation in which an asymmetry predominates where the Other is superior to the Same, which is based on 'responsibility' rather than the reciprocity of the relationship (Levinas, 1987).

In the face-to-face encounter, the Face – manifest part of the Other, the one that reveals itself to the Self and, at the same time, resists to its attempts at domination and power – shakes the foundations of the Same and questions its selfish freedom, forcing it to look outside itself and awaken the restlessness constitutive of subjectivity, which is the seed of the possibility of acceptance of the Other as well as responsibility for it. (Martinelli, 2015). The Face presents itself as an appeal, a cry that begs the Self not to exterminate it and calls it to an infinite responsibility, from which the possibility of the ethical response of the Self arises (Levinas, 1980). Whereas, the Self is not capable of becoming indifferent to the appeal of the Face, as this forces the Self to leave itself.

In contemporary society, there is a tendency to dull the Face (Levinas, 2001), represented, in the case of people with disabilities, by a totalizing ideology and social organization, dominated by medicalizing and normalizing perspectives that do not take into account diversity and differences and subject people with disabilities to multiple educational, physical, and attitudinal barriers as well as a consequent social exclusion (Diniz, 2007).

The primacy of ethics also precedes justice and politics. To Levinas (1980), the relation between the Same and the Face extends to a 'Third' – representation of all humankind –, which is introduced to the Self through the interaction with the Other. The singularity of the Other, which reveals itself through the Face, draws the attention of the Same to multiple singularities, to all the Others who need attention to their vulnerable condition. The cry of the Third forces the Same to go beyond ethical proximity to fraternity and to compare the incomparable in their singularity, establishing, through justice and politics, forms of equality. Thus, justice and politics are necessary, not as a static model, but rather constantly questioned by ethics, so that equality does not get stuck in ontological and political totalitarianism (Carrara, 2010).

Taking into consideration the centrality of ethical issues and alterity, Levinas's philosophy can contribute to the field of disability studies and the discussion of the concept of disability in at the present time, as it focus on the ethics of the relation between the Same and the Other, which calls the Self to infinite and asymmetrical responsibility for the Other without exhausting or nullifying justice and politics. This research, therefore, focuses on an investigation of scientific literature through the State of the Art on the relation between disability, ethics, and responsibility. Contributions from the field of Human Sciences, such as psychology, law, education, and philosophy, are considered, in combination with the thoughts of Emmanuel Levinas, proposing ethics as a hermeneutical key for interpreting issues related to people with disabilities.

Method

We conducted a State of the Art analysis of the concepts of disability, ethics, and responsibility in contemporary times, based on the contributions of Emmanuel Levinas's Philosophy. The State of the Art is bibliographic in nature and aims to map and discuss academic production on a given topic, analyzing which aspects and dimensions have been highlighted and privileged in different times and places (Ferreira, 2002).

In addition to the qualitative focus, the data received quantitative treatment, using the following bibliometric indicators: year, subject area, QUALIS CAPES of the journal, educational institution, and research group that the authors were linked to. This survey was subjected to scientometric analysis, which consists of measuring scientific progress through intercomparisons between the activity and productivity of different scientific publications (Silva & Bianchi, 2001).

The procedures adopted were based on the contributions of Ferreira (2002) as well as Romanowski and Ens (2006). Initially, we carried out a search for papers, dissertations, and theses available in the following databases: Scientific Electronic Library Online (SciELO); Portal of Online Journals of Psychology (Portal de Periódicos Eletrônicos de Psicologia - PePSIC); Brazilian Digital Library of Theses and Dissertations (Bases de Dados de Teses e Dissertações - BDTD) – chosen for their relevance to scientific and academic dissemination in Brazil. The combined descriptors were: disability; Levinas; ethic; responsibility.

The inclusion criteria to the data collection were: a) studies in Human Sciences, Legal Science, and Education; b) investigations concerning the discussions about people with disabilities, alterity, and ethics; c) theoretical and/or philosophical studies, empirical research, or intervention research; d) papers, dissertations, or theses published from 2009 to 2019; e) texts written in Portuguese; f) complete study available online.

Due to the limited time for research, it was necessary to adopt distinct procedures to analyze the papers and the dissertations and theses. For the papers, the following steps were carried out: 1) search in the databases based on the combinations ‘disability AND ethics’; ‘disability AND responsibility’; ‘disability AND Levinas’; ‘disability AND ethics AND responsibility’; ‘Levinas AND ethics AND responsibility’; 2) reading end selection of texts based on the titles and abstracts, considering the inclusion criteria aforementioned; 3) full reading of the texts; 4) synthesis and classification according to the research goals.

The dissertations and theses were collected in the BDTD database with the same combinations of descriptors, but they generated a large amount of material not directly related to the research goals. Thus, the researchers decided to specify the descriptor ‘disability’, dividing it into four descriptors – physical disability; blindness; deafness; intellectual disability. This division encompasses the most common groups of biological injuries or physiological impairments classified as disabilities, which helped to discriminate materials focused on the specificities of this work. It is important to emphasize that this option refers to time and budget constraints on the present study; therefore, it does not exhaust the complexity or the totality of studies and approaches on the topic, nor does it capture the singularity of the face-to-face encounter with the radical and infinite alterity of the person with a disability. Another modification was the exclusion of the full reading of the works due to the volume of pages and the limited time available for research.

Thus, for the dissertations and theses, the following steps were executed: 1) search in the databases based on the combinations ‘physical disability AND ethics’; ‘blindness AND ethics’; ‘deafness AND ethics’; ‘intellectual disability AND ethics’; ‘disability AND responsibility’; ‘disability AND Levinas’; ‘Levinas AND ethics AND responsibility’; 2) reading end selection of works based on the titles and abstracts, considering the inclusion criteria aforementioned; 3) reading of the theoretical foundation and conclusions, if there was not enough information in the abstracts; 4) synthesis and classification according to the research goals.

At the end of the collection procedures, the *corpus* was composed of 12 papers, 11 master's theses, and 4 doctoral dissertations, initially categorized in a quantitative-descriptive manner and subsequently analyzed qualitatively.

Results and discussion

Para facilitar a compreensão, a análise de dados foi subdividida em dois momentos: inicialmente, o material coletado foi analisado em termos quantitativos e cientométricos, com objetivo de observar a relevância científica das produções encontradas; posteriormente, foram observados os conteúdos qualitativos de cada artigo, em comparação com a obra de Levinas e dos estudos contemporâneos acerca da deficiência.

Como apresentado na seção de procedimentos metodológicos, os descritores foram combinados de forma a analisar a produção científica através da relação entre os conceitos de deficiência, ética e responsabilidade. Porém, também buscou-se entender como a filosofia de Levinas foi interpretada na última década (através da combinação de descritores ‘Levinas AND Ética AND Responsabilidade’), ainda que não estivesse diretamente relacionada ao conceito de deficiência. Tal divisão temática foi utilizada para a interpretação e categorização dos objetivos e resultados das publicações encontradas, uma vez que tais seções se modificaram em consonância com a temática enfatizada.

Scientometric analysis

The information and data collected from the works were categorized and described in the following sections, based on the number of publications per year, authorship, research groups, region of origin, journals, and areas of publication. Furthermore, we chose to highlight the theoretical foundation and objectives proposed by the authors in order to analyze the focuses prioritized in each scientific work.

Number of publications

The year 2017 stood out as having the highest number of works published (07 in total). In the other years, production varied between two or three works, with the greatest consistency being between 2013 and 2015, with two productions per year. It should also be noted that in the last decade no publications were found in the years 2009 and 2012.

Some factors may be associated with the increase in the number of works produced in 2017: in 2015, the Brazilian Law for the Inclusion of People with Disabilities (LBI) was approved, which guaranteed the adaptation of Brazilian legislation to the CRPD. Moreover, in 2016 the Brazilian law 13,409/2016 was implemented, making the reservation quota mandatory to grant access to higher education institutions to people with disabilities. Such legislative advances may have become triggers for the publication of research on inclusion and disability in Brazil in 2017, with a considerable decline in 2018 (02 publications) and 2019 (03 publications).

Authorship, research groups, and place of origin of the publications

The papers had a total of 28 authors and co-authors, and the theses and dissertations had a total of 15 authors (01 per work). There was no repetition of authorship among the publications, which represents, on the one hand, a diversity of authors with an interest in the themes investigated and, on the other, suggests the absence of study groups focused on the systematic development of such theoretical references.

The same diversity was identified regarding the research groups registered in CNPq to which the authors were linked: a total of 24 groups were observed, with no repetition occurring among publications. Only three authors were not linked to any research group, one of which is not Brazilian (Eric Plaisance) and had his paper translated; and two others were responsible for publishing master's theses (Jefferson Polidoro Dias and Cecilia Inês Tamiozzo). In the case of the theses and dissertations, the supervisors's links were also investigated when there was no direct link between the supervisee and a research group.

The results presented demonstrate that there are no authors in the last decade who have dedicated themselves specifically to research on ethics and inclusion regarding disability and Emmanuel Levinas. This finding is relevant to highlight the lack of authors and research groups that focus on this theoretical direction, which points to the need to develop more research to systematically connect such references.

Regarding the place of publication, a concentration was observed in the Southeast (12 publications in total) and South (10 publications in total) of Brazil; followed by the Northeast, with four publications, and the Central-West, with one publication. The institutions that presented the most author links were the University of São Paulo (USP) and the Federal University of Minas Gerais (UFMG), each associated with three publications. The scarcity of productions in the North, Northeast, and Central-West regions of the country indicates the need to discuss such philosophical references more comprehensively in Brazil. In the case of the Northeast, a considerable contrast also stands out: according to IBGE (2015), the largest number of people with disabilities in Brazil live in this region, however, it presents scarce scientific production focusing on disability, ethics, and responsibility.

Journals and subject areas

The QUALIS journal ranking system represents the relevance of a given journal to a subject area, whether international (category A) or national (categories B and C). Most of the papers were published in QUALIS A1 and A2 journals (09 papers in total), followed by B1 and B2 (03 papers in total). Thus, it is possible to conclude that the papers found were published in magazines with international and national relevance, which brings greater recognition and dissemination impact in the academic community.

As in the case of authorship, a diversity of magazines was observed, among which only two were repeated, namely: *Cadernos de Pesquisa* e *Ciência & Saúde Coletiva*, each with one publication. As for the areas, the theme of the publication itself was taken into consideration, that is, the article was selected if its theme fit into the themes of disability, ethics, and responsibility, even if the journal was linked to areas other than human sciences, legal sciences, and education. Thus, we noted a predominance of publications in the area of education (06 papers), followed by the area of psychology (03 papers).

As for the theses and dissertations, they were classified by subject area according to the postgraduate program to which they were linked. The area of education was also predominant (with 05 works), followed by law and philosophy (with 03 works in each area).

Our study shows that the area of education predominates when the focus is on the themes of disability and inclusion, which indicates the need to expand studies on the social participation of people with disabilities in areas such as culture, work, and politics. Emmanuel Levinas's thought, despite appearing related to educational inclusion, was also the focus of works in the areas of law and philosophy, mainly when dealing with the intersection between ethics and justice.

Theoretical foundation

As for the theoretical foundation, the publications, mainly the theses and dissertations, presented a diversity of authors and theories according to the specific objectives of each work. There was a predominance of theories that focus on ethics: in total, 21 works approached this theme, and the majority of them (15 works) applied elements of Emmanuel Levinas's Philosophy associated with other theoretical references. The subtopics of the works were: bioethics; ethics according to Emmanuel Kant; Habermas's Discourse Ethics; Research ethics according to Bruno Latour's theory.

The second most important basis among the works was that focused on the Social Model of Disability (06 works in total). The most cited author among these publications was Débora Diniz (03 publications), whereas two works used documents provided by the World Health Organization, which applies this perspective to formulate recommendations focused on people with disabilities.

Pertinent to this research, the anthropological approach also appeared in the works found, represented by Cultural Studies of Deafness, a perspective that affirms deafness as a difference, a specific way of experiencing the world that must be respected in its uniqueness – defended by authors such as Carlos Skliar and Karin Strobel. Moreover, there is a focus on the theme of justice, with emphasis on the thoughts of authors Emmanuel Levinas, Jacques Derrida, and Amartya Sen.

Methods

Most of the papers found (11 in total) were classified as theoretical productions, belonging to the essay genre (07 papers). These works were categorized according to the authors's own indications or, when the method was not explicit, according to the textual characteristics. The other methods used – ethnographic report; theoretical-practical analysis; critical discourse analysis; and theoretical-conceptual study – were covered by one paper each. Only one work was characterized as an empirical study, using the qualitative research approach and the semi-structured interview technique.

The theses and dissertations consisted, for the most part, of theoretical publications (10 works in total), with the bibliographic review method being the most expressive (05 works), followed by hermeneutics (03 works). The empirical research was mostly qualitative (04 works), developed using the ethnographic method and the semi-structured interview technique. Only one thesis adopted both quantitative and qualitative methods, using bibliographic review, document analysis, and the application of questionnaires as techniques.

The characterization of the methods and approaches applied allows us to observe a greater quantity of qualitative productions, focused on the bibliographical review and theoretical analysis of other works already published. Thus, this finding points to the lack of empirical and practical application studies focused on the intersection between ethics, responsibility, and disability.

Objectives

The analysis of the objectives of each publication was subdivided according to the subject approached. Seventeen out of the 27 works collected directly approach the disability issue, whereas nine focused on the comprehension of Emmanuel Levinas's philosophy. This difference is justified by the methodological choice for this research, considering that the focus is on discussing disability at the present time.

The works that approach people with disabilities had their objectives subdivided into three groups: 1) theoretical reflection on the relationship between ethics and inclusion: the authors focus on the importance of discussing ethical positioning, consideration of difference, and responsibility for the Other on issues concerning inclusion; 2) critical analysis of the current participation of people with disabilities in society: the authors seek to affirm the damage that biomedical and normalizing perspectives cause to the effective participation of people with disabilities; 3) critical reflection on the guarantee of rights and services for people with disabilities: the authors discuss social and ethical responsibility involving care, education, and research, in addition to problematizing the effective guarantee of rights and the current way of making legislative decisions, which currently excludes the active participation of people with disabilities.

On the other hand, the works based on Levinas's philosophy focused on the following themes: 1) the Face as an interpellation that generates the infinite responsibility of the Self towards the Other; 2) alterity and recognition of the Other as fundamental ethical principles to achieve social inclusion in diverse areas, such as education and law; 3) analysis of the concept of justice and its relationship with Levinas's philosophy; 4) analysis of the philosophical-religious foundations that supported Levinas's ethical thought.

Main results of the publications

Described in the following sections, the results of the work were categorized according to the similarities between them. We noted a critical stance by the authors regarding the reality of oppression faced by people with disabilities, both in terms of exclusionary and discriminatory attitudes (‘Totalization of disabled alterity at the present time’), and the insufficiency of public policies and legislation focused on this population (‘Insufficiency of current interventions’). Another point of convergence was the pointing out of the need to abandon theoretical-philosophical conceptions aimed at the normalization of subjects and the suppression of singularity (‘Recognition of difference/Abandonment of normalization’), related to the adoption of concrete measures, which go beyond theoretical knowledge (‘Need for practical/concrete measures’).

Totalization of the disabled alterity at the present time

Among the main results of the publications, there was a criticism of the exclusion and totalization of the alterity of people with disabilities at the present time. Mello (2016) denounces in his article how ethics committees adopt biomedical perspectives when analyzing research directed to people with disabilities, treating this population as ‘incapable’ of responding for themselves and disregarding the principles defended by the CRPD of dignity and freedom to make their own choices.

The totalization of people with disabilities also occurs through an ideology of normalization, which happens, for example, when the disabled body is disregarded in social discussions. Accordingly, Sella and Muller (2011) criticize the way in which discourse ethics is used only for people who are able to speak for themselves openly, disregarding the alterity and specificity of the disabled body – such as people with severe intellectual disabilities, which present different forms of communication.

The same ideology of normalization appears when analyzing the discourses present in Brazilian legislation, state Tavares, Duarte, and Sena (2017). The authors denounce the fact that Brazilian laws reveal ideological struggles between the biomedical paradigm and the Social Model of Disability because, even though they depart from the social model, their texts focus on the normalization and adaptation of people with disabilities to social mechanisms instead of proposing a modification in culture to promote effective social participation.

According to Levinas's philosophy, one can infer the denunciation, made by the different authors mentioned above, of an alleged universalism – through which it is assumed that all people are equal and have the same needs – which results in the totalization of the alterity of people with disabilities through a blunting of differences and consequent social exclusion of singularities (Levinas, 2001).

This attempt at totalization is the result of perspectives centered on the Ontology of the Same, in which the Self becomes the core of discussions to the detriment of the ethical relationship with others (Almeida, 2013; Ribeiro, 2015). The consequence, as highlighted in the following section, is the development of collective and social actions that do not consider the singularities and specific needs of people with disabilities, leading to discrimination, exclusion, and erasure of the Other's differences.

Insufficiency of current interventions

Another factor highlighted by the work was the insufficiency of current actions, interventions, and services for people with disabilities. Tavares et al. (2017) conclude that actions focused on children with disabilities are incipient, and the analysis of their application demonstrates funding restrictions on the part of the government. This data is corroborated by Coutinho (2017), who notes the insufficiency of the care, provision, and protection network of current Brazilian inclusion policies, imposing on the family, especially mothers, the responsibility for the ‘profession of care’.

Arantes (2017) expands the discussion of the insufficiency of guaranteeing the rights of people with disabilities by analyzing their insertion in the community. The author argues that, in addition to the physical barriers that impede accessibility, there are attitudinal barriers, such as prejudice and discrimination, which hinder the effective social participation of this population.

Finally, discussing the issues surrounding research, Pereira (2015) highlights the lack of feedback on scientific research carried out with both caregivers and managers of institutions serving people with disabilities, pointing to the need for ethical reflection of researchers when studying groups in vulnerable situations.

Recognition of difference/Abandonment of normalization

The recognition of the Other as different from me is pointed out by the authors as the fundamental ethical principle for leaving the ideology of normalization, which promotes the totalization and concealment of alterity. Normalization as an ideology is only overcome through the preservation of a heterogeneity that respects differences and does not require the Other to be similar to the Self (Tonatto, 2017).

The adoption of an ethical stance and direction leads to the recognition of disability in its positive aspects, considering the subject in their needs and potential (Santos, 2016a). This direction implies, in the educational sphere, the consideration that the differences between subjects are not an impediment to the right to learn together, which helps to promote a new pedagogical praxis that respects singularity and focuses on an education that promotes human formation.

Furthermore, the ethical recognition of alterity helps in the stance adopted in research with vulnerable groups as it removes the researcher from the place of knowledge and superiority as well as establishes the positioning of the research subject as essential for obtaining consent and for developing the writing of academic works (Figuerêdo, 2015).

Need for practical/concrete measures

The principle of ethics, associated with the abandonment of the ideology of normalization, is contrasted with the need to adopt practical measures that concretely impact the daily lives of people with disabilities. It is necessary to rethink the negative way in which disability is still conceived at the present time and start to understand it positively in its potential (Santos, 2016a). However, taking this position must go beyond the discourse of inclusion and materialize into practical measures that favor the effective participation and belonging of individuals with disabilities in society (Plaisance, 2010).

Thus, the authors Dainez and Smolka (2014) argue that Vygotski's historical-cultural theory is relevant to the study of disability, considering that it stems from the understanding of the subject in their social and concrete life conditions to propose the need for interventions that socially and culturally compensate for the organic limitations of people with disabilities.

Ethics therefore is only effective in the field of practice, as it is a response to the demands of the Other. It is at this point that justice and the guarantee of human rights meet since more than taking dignity, difference, and uniqueness as principles to be ensured, practical actions are necessary, such as the training of professionals in ethics and human rights, and interventions that take into account the needs and specificities of people with disabilities in the fields of education, health, and law, as well as research with vulnerable groups (Farinon, 2018; Figuerêdo, 2015; Pozzer, 2013).

Implications of the Emmanuel Levinas's ethics of alterity

The results found also demonstrated the authors's own view of Emmanuel Levinas's thought as well as the implications inherent to this perspective. The ethics of alterity, more than a theory, is a principle and a horizon to be achieved, demanding non-indifference, the abandonment of the privileges of the Self, the recognition of the Other as different from me, and the infinite responsibility for the Other as the basis for action (Farinon, 2018).

Therefore, the works analyzed contain the idea that responsibility should be reflected not only in face-to-face relationships, but also in teacher-student and researcher-subject relationships, or in interpersonal relationships in general (Pozzer, 2013; Santos, 2016a), but also within the scope of justice, legislation, and public policies.

It is at this point that the figure of the Third appears in Levinas, which represents the need to create regulatory principles of society that are based on intersubjective relationships, but that also go beyond it to broader dimensions, such as politics, law, and legislation (Dias, 2016). The commitment to alterity, even if carried out within the scope of the state, results in the impossibility of neutrality. The responsibility requires an ethical positioning of the Self, a response of hospitality towards the Other (Lazzari, 2019). According to Pozzer (2013), this responsibility is expressed even more when it is focused on human beings who have had their alterity wounded or denied, as in the case of people with disabilities in the scope of the present study.

Justice materialized from ethics would therefore be characterized by the same principles of acceptance, responsibility, and solidarity towards the most vulnerable within society (Dias, 2016). According to Zevallos (2014), such principles presuppose, then, the constant questioning of the universalizing and normalizing possibilities established by current legislation and policies, making justice and ethics translate into horizons to be achieved, impossible to reduce to a single model.

Qualitative analysis

Disability, ethics, and responsibility based on Emmanuel Levinas's philosophy

The studies found in the last 10 years (2009-2019) on the relation between ethics, disability, and responsibility point to the existence of exclusionary, discriminatory, and totalizing attitudes towards the alterity of people with disabilities at the present time, in addition to public policies and legislation with insufficient application in promoting the guarantee of basic rights for these people in Brazil. The works also point to the need to recognize difference and singularity as a basis for abandoning normalizing ideologies, associated with concrete measures to guarantee dignity and combat the exclusion of the population with disabilities on a legal and political level.

According to Levinas (1980), it is from the relationship of proximity – developed through the face-to-face encounter between the Self and the Face – that the ethical response of infinite responsibility of the Self towards the Other in their vulnerability arises. The ethics of alterity is centered on the recognition of the radical difference of the Other, not only in its fragility, helplessness, and indigence, but also, absolutely inseparably, in its height (Levinas, 1980), which prohibits reciprocity in proximity (Ribeiro, 2015; Menezes & Reis, 2009). Thus, the starting point for inclusion is the recognition of others and their irreducible difference, which begins with proximity and acceptance.

The legal and political dimensions, when configured as a way of universalizing the needs of people with disabilities, prove to be insufficient to guarantee interventions and actions that actually benefit specific people in vulnerable situations. For this reason, justice and politics, as proposed by the author, cannot occur in an untouchable manner, but must always be questioned and revised based on the ethical relationship that preserves the asymmetry and height of the Other (Levinas, 1987, 1988). The fight for equality and citizenship does not annul the infinite responsibility for others; on the contrary, it must emerge from the ethics of alterity and the recognition of the radical difference of people with disabilities, taking into account that the objective is not diminishing the importance of others, but guaranteeing it based on relationships of proximity and fraternity (Duque, 2015). The equality of justice and politics arises from the inequality of ethical proximity, which opens up the possibility of a fraternal relationship with others (Levinas, 1987). It is in the constant tension between ethics, justice, and politics that the heterogeneity of the Other is preserved and the tendencies towards the totalization and normalization of difference are combated.

The CRPD and the ICF guarantee social, economic, civil, and political rights to people with disabilities. However, public policies based on affirmative actions, which are the way to apply such laws and achieve the full social participation of people with disabilities, have proven to be insufficient in terms of implementing these structural changes in contemporary society (Souza, 2013). Therefore, attention must be paid to the risk that justice and politics, when distant or dissociated from ethics, only serve to blunt and deny difference (Bensussan, 2009) and create a simulacrum of inclusion for people with disabilities (Diniz et al., 2009).

As challenging as it may be, in Levinas, ethics is not linked to Aristotelian teleology or Kantian deontology, both centered on rational ontological conceptions of the human (Rial, 2015). Ethics in Levinas is part of alterity, sensitivity, and substitution (Levinas, 1980, 1987). Sensitivity occurs in proximity to others and their difference. Thus, it is necessary to carry out a reversal from ontology to primary ethics. The face-to-face encounter must precede the representations, the preparation for the intervention for justice, and human rights and begin with the singularity of the nakedness of the Face. Therefore, the legislative dimension must be in a constant process of review and questioning, based on the uniqueness of the Other – represented, in this case, by people with disabilities. The ethical dimension - which emerges in the face-to-face encounter through sensitivity to others and provokes a response of infinite responsibility (Levinas, 1980) - acquires, in the view of the authors of this work, a centrality in the promotion of inclusive actions and practices, as that it is from this dimension that it is possible to assume a stance of hospitality to the Face that presents its needs to the Self.

Based on the discussions proposed in this work, it is possible to affirm that the philosophy proposed by Emmanuel Levinas is useful to question the issue of exclusion of people with disabilities beyond legal and political aspects. Levinas invites the Self to stop looking at itself, leave its position of comfort, and assume infinite responsibility for the appeal of the Face that presents itself face-to-face. Thus, it provokes people and society as a whole to leave their normalizing and universalizing bases.

Final considerations

Despite the legislative advances in favor of people with disabilities, the dominant social ideology, supported by a ‘normality culture’, creates discriminatory barriers that prevent the effective social participation. The need to rethink society's involvement in eliminating the oppression experienced by individuals with disabilities was the starting point of this research, which aimed to discuss the concept of disability at the present time based on the contributions of Emmanuel Levinas's philosophy.

Taking into consideration the analysis of the results found, we noted the existence of attitudinal, educational, and cultural barriers that exclude people with disabilities from social participation. This observation falls on the need to replace totalizing and universalizing conceptions of differences – still dominant at the present time – with perspectives of recognition of the Other and consideration of human singularity and multiplicity. Thus, according to the analysis developed in this research, Levinas's philosophy is relevant, taking into account that it proposes leaving oneself and committing to infinite responsibility for the Face that reveals itself and calls for help, operating a decentering of subjectivity.

The results obtained in this study help in reflecting on the dominant ontological perspective in Western culture, characterized by individualization, autonomy, independence, which results in the social exclusion of those in vulnerable situations, such as people with disabilities. Emmanuel Levinas's philosophy invites to the involvement of the Same with the Other, to help without waiting for reciprocity, making it relevant as a theoretical-practical foundation in the field of disability studies. At the same time, such principles need to be considered at broader levels of law and legislation, considering fraternity towards others, so that justice can actually be achieved.

In general, it was possible to observe a lack of investigations that directly relate studies of disability with the ethics of Levinas's alterity. This highlights, therefore, the need to develop a higher number of investigations that take into consideration the relations between Levinas's Ethics of Alterity, justice, and politics as a basis for reflections and practices of inclusion and social participation of people with disabilities.

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