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## EXPRESSIONS OF THE ETHICS OF CARE IN RESEARCH PROCEDURES: AN EXPERIENCE REPORT

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**Abstract:** Research carried out in the field of disability commonly uses homogenizing methodological procedures, which do not accommodate the diversity of characteristics of the investigated subjects, prioritize the modes of participation as another expression of the ableism that is present in our society and do not respect differences in the way of expression and participation of each subject. The objective of this work is to share the experience of two researchers, at the doctoral level, who used methodological procedures organized from the contributions of the Universal Design for Learning in order to break with capacitativist and homogenizing practices that are often used in the collection of information and enable a care action in scientific practices. Establishing procedures respectful of the characteristics of the investigated public is a recognition by the academy of the oppressive conditions of scientific production itself. In the same way, reflecting on the production of knowledge based on elements of disability studies from a feminist perspective is to propose attitudes based on human rights, the ethics of care and social justice in the scientific field.

**Keywords:** Deficiency, Ethics of care, Methodological procedures, Universal Design for Learning, Feminist Studies

## INTRODUCTION

In different countries, there are researchers focusing their studies in order to qualify and, consequently, expand the understanding of issues involving the theme of disability, whether in the Human Sciences, Social Sciences, Health, etc. However, a hierarchical relationship is commonly perceived between the researcher and the Subject/object of the research. Therefore, we understand that there is a need to break with normocentric practices in research contexts, which subordinate certain subjects as an expression

of structural ableism so that we can reflect on ways of doing more respectful research together with people with disabilities.

The experience report proposed in this article brings together the path of two doctoral researchers, in the Postgraduate Program in Psychology at the Federal University of Santa Catarina - UFSC (BOCK, 2019; SILVA, 2020). The two researchers are allies in the anti-capacitivist struggle and, for that, they seek to imprint in their research a theoretical/methodological coherence. There is, by both, an understanding that dependence is something inherent to the human condition, something lived and experienced in different social contexts, and thus, committed to the right of participation of all, they sought research techniques and support resources that provide accessibility and participation as an expression of the ethics of care in the university space.

Understanding that the advantages or disadvantages of participation with agency are relational to the contexts is that, when thinking about academic research, it is necessary to be sensitive to the modes of participation of all people and, for that, to incorporate data collection procedures and analysis methodology consistent with the valorization of these different ways of participating.

In order to provoke a reflection among researchers in the field of disability, we propose to open a dialogue, which, in this article, will be distributed with the following organization: first, we will present some theoretical/conceptual bases that guide our practices as researchers, in a secondly, we will present a brief report of the doctoral studies, and finally, we will bring a discussion about coping with ableism from the incorporation of the ethics of care.

## **THEORETICAL AND CONCEPTUAL BASIS - CAPACITISM AND ETHICS OF CARE**

Capacitist practices have permeated the different spaces of scientific production, whether in the absence of researchers with disabilities in different areas of knowledge, or even in the relationship of researchers in the field of disability with research subjects, who often treat subjects as objects of analysis and are sometimes not very sensitive to the opinions and conditions for participation of these people. Still, there are not few productions that, after using the experience of disability for their analyses, end up producing texts, whether articles, dissertations or theses, which are not accessible to the reading of the investigated public.

Ableism is structural and structuring, that is, it conditions, crosses and constitutes subjects, organizations and institutions, producing ways of relating based on an ideal of subject that is performatively produced by the compulsory reiteration of normative capacities that consider women's bodies, people black, indigenous, elderly, LGBTI and people with disabilities as ontologically and materially deficient. (GESSER, MELLO and BLOCK, 2020, p.18)

Normocentrism, which is so engendered in social structures, naturalizes research practices that are excluding, which dominate and colonize bodies, hierarchize voices to be heard and considered as legitimate for the analysis of studies. It is quite common to observe the participation of people with disabilities in studies on disability, which is not a reality if we observe studies with other approaches, areas and themes. We have statistical data (IBGE, 2010) that indicate that 6.7% (12.5 million) of Brazilians are characterized as people with disabilities, however these numbers are not replicated in the proportion of their existence in the participants of most academic research. According to Friggi Ivanovich and Gesser

(2020) "the imperative of normality tends to be reiterated through the omission of social institutions that must guarantee and enforce the rights of people with disabilities, but which end up delegitimizing claims" (p. 07).

Angelucci, Dos Santos and Pedott (2020) provoke us to reflect, indicating that the low representation of students with disabilities in higher education implies, consequently, the limited training of researchers with disabilities. This issue reveals that this sector of the population is relegated to the condition, at most, of participating in research carried out by people without disabilities (p. 57).

As higher education teachers from a public institution, we feel provoked in the anti-capacitative struggle, in the sense of promoting practices that are emancipatory and respectful of human diversity, and, as Angelucci, Dos Santos and Pedott (2020) rightly point out, "it is a condition In order to guarantee the participation of people with disabilities in research, we appropriate forms of communicational accessibility and, based on that, we invent methodological and procedural approaches that are in line with the rights of people with disabilities" (p.67).

According to Friggi Ivanovich and Gesser, (2020) "A praxis aimed at human emancipation and at the service of the demands of people with disabilities requires constant questioning and presupposing an a priori not knowing, but built together with the people with whom they interact. works (p.18). Based on what has been said about ableism in the research space, it is understood that there is an urgent need for practices that consider care as a starting point, in order to break with negative, stigmatizing and subordinate beliefs about the experience of disability.

Care has its roots in a conception as a function limited to the female and the exclusive responsibility of the family. Opposing this idea, Kittay (2011) proposes

to break with this private logic of care and its essentialism as a woman's task and brings the understanding of care as well as obligation and social responsibility. When approaching the care of people with disabilities, she recognizes dependence as a human condition and care as a virtue. Care moves from the scope of disability to be a central element in the relationships between people with and without disabilities. For the author, an ethics of care is needed, which goes beyond intimate and private relationships to become a public ethics, considering that everyone establishes a relationship of "nested dependence" (KITTAI, 2011, p. 55, our translation). It brings dependence as part of the human life cycle and care as a promoter of well-being and a dignified life for all people. With this, it removes the negative character commonly directed to care and the person cared for as worthy of pity and without the right to position themselves in the face of their own care.

Because care and dependence are rooted in a vision in which human dignity is linked to the capacity for autonomy and well-being, people with disabilities who depend on others for their self-care and well-being seem to have their dignity threatened (KITTAI, 2011). The author, from the perspective of an ethics based on inclusion, proposes that the look be shifted to the dependency relationships that all people have at different stages of life and health and functioning conditions, leaving the disabled person no longer as an exception or special situation. With this, she proposes that care be brought to the public sphere and that it be transversal to all policies. It proposes an ethic of care to develop and refine normative characteristics at work, attitude and disposition (KITTAI, 2011). To do so, she addresses the meanings that the term care brings, such as work, attitude and virtue.

Like work, it is the exercise of supporting ourselves and others when we are in a condition of need. It requires skills on the part of the caregiver and acceptance on the part of the caregiver. [...] As an attitude, caring denotes a positive affective bond and investment in the well-being of the other. The work can be done without the proper attitude. However, without the attitude of caring, the open receptivity to the other that is so essential to understand what the other requires is not possible. [...] Care, as a virtue, is a disposition manifested in the behavior of caring (the work and the attitude), in which "there is a change of interest in our life situation to the situation of the other, the one who needs care". care" (Gastmans, Dierckx de Casterle, and Schotsmans 1998, 53). Affectionate relationships facilitate care, but the disposition can be directed to both strangers and intimates. (KITTAI, 2011, p. 52-53, our translation)

This author displaces care from the scope of benevolence and places it as social justice, considering it as part of human nature in which interdependence is a condition of all people.

Fietz and Mello (2018), when discussing care as a practice that has multiple versions that coexist and integrate, suggest three aspects identified in their studies: care as overprotection, care as education and care as violence. They approach care as a job and an attitude. There is a moral aspect to care that brings values that shape attitudes. It is important in care to listen to the other, to see what their needs are, to allow the person to decide about their own body and what they want, not to create dependencies that would not be necessary. Care needs to be built on the relationship between caregiver and person cared for and to recognize the active role of all people involved in this relationship. They clarify that it is "necessary not to assume the most appropriate type of care based on general precepts, but rather that it is a daily co-construction", considering that it is movement

and not “something stabilized” (FIETZ and MELLO, 2018), p. 134).

Zirbel (2016, p. 84) reaffirms the importance of care leaving the personal field and moving to the political field. Supported by Eva Kittay, she describes the “doulia state”, making a parallel with the doulia that help during pregnancy, childbirth and postpartum, providing physical, emotional and informational support. With this, it relates to the idea of “well supported dependencies”. She clarifies that autonomy is always relational.

Given the above, it is clear that the lack of care is also present in the academic research process. Subjects are often placed in a passive position, as “research objects” to obtain information. Research based on the Universal Design for Learning (DUA) proposes other ways of doing research, bringing the ethics of care to the process. To this end, we present below two examples of doctoral research, carried out in the Brazilian context, whose researcher brings the principles of the DUA in her practices and, with that, meets a proposal based on the ethics of care, reinforcing the anti-capacitation practice in her research.

## **BRIEF CONTEXTUALIZATIONS OF DOCTORAL RESEARCH**

**Research 1:** Universal Design for Learning and its contributions to Distance Education. The online qualitative approach research (FLICK, 2009), in the exploratory and descriptive modality, inspired by emancipatory studies, aimed to identify contributions of the Universal Design for Learning (UDA) to face and eliminate methodological barriers present in educational environments. the distance. The DUA principles suggest that accessibility must prioritize aspects of learning, promoting environments that are more welcoming to human differences.

The online qualitative research took place in the virtual space of Moodle, and the

choice of this method is due to the fact that it is consistent with the phenomenon to be investigated, with the reception of different participants and with the characteristics of the researcher. According to Flick (2009), this research approach offers some advantages, such as saving resources and time, such as transcriptions of participants’ speeches or displacements of participants and researchers, in addition to providing different ways of participating. (synchronous and asynchronous).

Ethical procedures for carrying out the online survey were duly carried out. All participants had access to the Free Informed Consent Term - TCLE in LIBRAS, audio and textual, revealing how data collection and procedures would occur to preserve the privacy and identity of each one who was available to participate in the proposed studies. It followed the ethical precepts contained in Resolution no. 510/16, approved by the National Health Council, which deals with the ethical aspects of Human and Social Science research.

From the general question, specific questions arise and each one of them generated a study that collaborated to answer the main question, namely:

Study 1 – Universal Design for Learning: Scientific production from 2011 to 2016 (BÖCK, GESSER AND NUERNBERG, 2018).

Study 2 – Universal Design for Learning as a principle of care in teaching practice (BÖCK, GESSER AND NUERNBERG, 2020).

Study 3 – The Universal Design for Learning in welcoming the expectations of participants in Distance Education courses. (BÖCK, GESSER AND NUERNBERG, 2019).

Study 4 – Contributions of Universal Design to Distance Learning Learning. (Awaiting evaluation).

The studies revealed that the DUA is in line with the principles and purposes of the

*Disability studies in education*, in addition to offering important contributions to the construction of educational practices in distance education aimed at welcoming human variation that go beyond the limits of disability diagnoses.

In addition to the study on the DUA, the adoption of data collection techniques that started from the dimension of care proved to be extremely appropriate, that is, anticipating the removal of barriers to the participation of all, and incorporating their own principles and DUA guidelines in research, providing different ways of accessing information and giving feedback, ensuring access to audio, text and LIBRAS at all times. Finally, the thesis was defended with a LIBRAS interpreter and, in the written text, the description of all the images was adopted and a language that could be accessible to all people and not only to doctors in the academies.

**Research 2** - Accessibility for Students with Autism Spectrum Disorder in Higher Education (SILVA, 2020). In an attempt to start a methodological process based on the DUA, considering the ethics of care in research, it was composed of two studies: the first documentary (SILVA et al., 2019, 2020), based on the analysis of INEP data (2017) and the second, exploratory-described qualitative. In the second study, the participation of autistic individuals was the main focus.

The context of this research was the virtual environment, available for internet access, questionnaires and online interviews. This choice was based on Feldman (2013) who affirms the advantages of interpersonal communication mediated by the computer and the internet for people with autism, as he considers it to be more comfortable due to the fact that it reduces the level of stress and anxiety about noise, physical contact and face-to-face, in relation to confused

facial expressions, and can do so in a safe and controlled environment.

In addition, the use of the virtual environment made it possible to adapt the way of expression of the participant in the interview according to their need or preference (by email, by WhatsApp [writing], by WhatsApp [voice], by Hangout [without camera], by Hangout [with camera] or other means), thus responding to the premises of Universal Design for Learning and an ethics of care in the field of academic research.

In order to break with the very common logic in academic research of doing “FOR” the other and not “WITH” the other (ALVES, 2016; MORAES, 2010), although in an initial proposal, this research had the participation of the students with disabilities from the construction of research instruments as content judges to the collection of information. Added to this, the care expressed in the tools used for the online interview that best suited the predilection and/or specificity of the participants and the fact that the research proposal arises from the experience lived with autistic academics in higher education and has as theoretical basis the second generation social model of disability.

It is certain that the process is still in its infancy in the fight against ableism in academic research. However, this proposal, considering the relevance of the researched theme, the care in collecting information, as well as the participation of autistic people in the process, was praised by the participants, like Eros (fictitious name of the research participant), in their final acknowledgments: “thank you, no one had ever worried like this before. I hope this helps a lot of people who can’t speak” (SILVA, 2020a, p. 187).

At the same time that Eros’ speech marks the realization of the aforementioned research with principles of the ethics of care, it denounces how much academic research

is disrespectful to the participants in its investigative processes.

## **THE ETHICS OF CARE IN COPING WITH ABLEISM IN THE RESEARCH SPACE**

The Universal Design for Learning is in line with the principles of the ethics of care and, through these, breaks with part of the ableism that underlies academic research in a proactive practice, which anticipates possible support needs for autonomous participation. When researchers follow the principles of Universal Design for Learning, accessibility is the starting point and, thus, allows all students or other participants to fulfill their right to participate, without restriction or difficulty in accessing the entire context that involves the educational space, establishing a relationship that contemplates the specificities of human variations. For Bock et al. (2019, p. 14), it is “relevant to incorporate the principles and guidelines of the DUA as a horizon for implementing the principles of ethics of care”.

This way, we believe that the ethics of care allied to the DUA must be the principle of all research in the academic environment, allying itself in the anti-capacitist struggle. However, this has not happened, in most research subjects are simple objects of analysis, data collection and are in a position of passivity. We agree with Angelucci, Dos Santos and Pedott (2020) that there is an urgent need for scientific research to commit to the participation of people with disabilities in their work, “whether constituting policies to encourage the training of researchers with disability, whether producing articulations between researchers and social movements, or introducing disability as an analytical category of the studies carried out” (p. 67).

In the fight against oppression, in different areas, it is urgent that our practices reflect

our discourses, it is not enough to theorize about accessibility, inclusion and even about ableism and continue to reproduce practices that exclude and do not emancipate subjects. Paraphrasing Angela Davis (2018) in suggesting the need for anti-racist practices to combat the oppression of racism, we can infer that in a capable society we need anti-capacitist practices. In the academic field, it is urgent that the research space is open to welcome the experience of disability and, with this, to provoke and consolidate research that respects human diversity.

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