

The reframing of disability through literature: the impacts of the Laboratory of Humanities on mothers of people with disabilities

A ressignificação da deficiência pela literatura: os impactos do Laboratório de Humanidades em mães de pessoas com deficiência (resumo: p. 17)

La resignificación de la discapacidad por la literatura: los impactos del Laboratorio de Humanidades en madres de personas con discapacidad (resumen: p. 17)

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This study aims to show the impacts of literature on mothers of people with disabilities, with regard to the reframing of their condition of “special mothers,” based on participation in the activities carried out at the Laboratory of Humanities, which is part of the Center for History and Philosophy of Sciences Health, at the Federal University of Sao Paulo, Brazil, whose purposes are to awaken affections and feelings and promote humanization, through the collective discussion of existential themes raised by classic works of universal literature. Three qualitative methodologies were applied after the reading of the fable “*Um Apólogo*” (An Apologue), by Machado de Assis: LabHum’s methodology; Oral Life Story; and Participant Observation. The results indicate positive transformations in perspectives and re-elaboration of humanistic values about the role that these women play as citizens seeking to broaden the debate on the social inclusion of people with disabilities.

Keywords: Disability. Humanization. Laboratory of Humanities. Literature.



Introduction

The International Classification of Functioning, Disability and Health (ICF), of the World Health Organization (WHO), defines disabilities as “problems in body function and structure such as significant deviation or loss.” They “correspond to a deviation from population patterns generally accepted in the biomedical state of the body and its functions,” and can be “temporary or permanent; progressive, regressive or stable; intermittent or continuous”¹.

The Portuguese term “*deficiência*” comes from the Latin *deficientia*, which means lack or absence, but also weakening and failure. And if in the health area deficiency represents a significant deviation or a loss of functions, whether physical or intellectual, in social contexts its meaning goes beyond the vernacular and stays close to its etymology.

In her book “What is Disability”, Débora Diniz writes that being previously the subject

of a strictly biomedical field, restricted to medical, psychological and rehabilitation knowledge, disability has also become a subject of the humanities². (p. 9)

Diniz explains that this broadening of perspective, described as an “academic shift,” originated in the United States and the United Kingdom in the 1970s, when new paradigms were established for understanding disability, which today

it is no longer a simple expression of an injury that imposes limitations on a person’s social participation; disability is a complex concept, which recognizes the injured body, but also denounces the social structure that oppresses the disabled person². (p. 9-10)

According to estimates by the United Nations (UN), one in five people worldwide are affected by some type of disability. In absolute numbers, it means almost 1.5 billion people.

In Brazil, the 2010 Demographic Census indicated that 45.6 million people – or almost 24% of the population at the time – reported having at least one type of disability. In 2018, the Brazilian Institute of Geography and Statistics (IBGE), responsible for conducting the Census, issued an analytical review technical note of this data after adopting in full the guidelines of the Washington Group on Disability Statistics (WG), linked to the UN Commission Statistics Office. The review, based on WG’s new cut off criterion, reduced the number of persons with disabilities in the country to 12.7 million – or 6.7% of the population. This figure is close to the 12.4 million people with disabilities – or 6.2% of the population – obtained by the 2013 National Health Survey (PNS), also conducted by IBGE.

Although the International Convention on the Rights of Persons with Disabilities, approved by the United Nations General Assembly on December 13, 2006, and ratified by Brazil on August 25, 2009, guarantees to persons with disabilities the same treatment given by society to other citizens, what is observed is that almost 80% of the 168 signatory countries still do not fulfill the goals of guaranteeing equal civil rights, such as right to health, education and work for persons with disabilities³.



In addition to the lack of effective public policies for ensuring the inclusion of people with disabilities in society, in all fields, social exclusion challenges also affect to some extent family members and/or guardians. This is because they also tend to become people with specific needs, lacking guidance and access to support groups. “In fact, they are the ones who will mediate the integration or inclusion of their children in the community”⁴ (p. 53).

Regarding the family’s role in this inclusion process, the literature shows that

the presence of a disabled person in the home [...] will demand, of each family member, a redefinition of roles and a change [...]. There will always be exceptional needs – for time, family restructuring, changes in attitudes and values and new lifestyles⁵. (p. 86)

Vieira *et al.*⁶, more specifically, show that

the mothers of children with cerebral palsy, in particular, have to face different situations, such as changes in their professional lives and finances, for example; [...] free time is reduced, due to the overload of care provided to the child, such as dressing, feeding, cleaning, accompanying to treatments and consultations; there are also feelings of guilt and isolation, reducing their social and cultural contacts; in addition, there are social and psychological limits, and society’s attitudes towards persons with mental disabilities are generally negative⁶. (p. 58)

With regard to the mothers, it is not uncommon for them to be forced to give up their desires and projects, both personal and professional, to dedicate themselves to the care demanded by the limitations of their children.

This situation reinforces an urgent need: these women will have to acquire special knowledge and an understanding of the dynamics of human behavior, of transformative phenomena and of the psychology of everyday life. Only by expanding their knowledge and through the feelings they bring with them, hope, will they be able to carry out creative actions⁵ (p. 93) to face a reinvented and adapted routine.

Considering, therefore, that the families of persons with disabilities need to provide assistance to their loved ones, while seeking some form of support for performing such task, it is expected that initiatives to meet these needs are relevant and will have a positive impact on their lives.

In this sense, humanistic approaches and actions can enhance this feeling of being supported and help any emotional, psychosocial, cultural and professional barriers caused by their children’s disability to be mitigated or experienced from a less discouraging and, perhaps, more optimistic perspective.



This possibility brings to mind the concept of humanization formulated by the French philosopher Charles-Louis de Secondat, known as Montesquieu, in “Essay on Taste”⁷, understood as “expanding the sphere of the presence of being,” in a translation by the thinker Teixeira Coelho.⁸ And this also allows initiatives such as the Laboratory of Humanities (LabHum), of the Center for History and Philosophy of Health Sciences at the Federal University of São Paulo (CeHFi-Unifesp), to fulfill this role, helping this reality, which leads to depersonalization and dehumanization, to be transformed into opportunities for resuming contacts with an “inner self” disfigured by the stigma of disability in the family.

The Laboratory of Humanities

The Laboratory of Humanities is a shared reading and rereading experience that emerged in 2003, at the Paulista School of Medicine (EPM-Unifesp), whose goals are to awaken the affections and feelings of the participants and foster humanization through the collective discussion of existential themes raised by classics of universal literature – which are at the center of the LabHum dynamics.

And why choosing the classics to the detriment of contemporary works?

In his book “Literature as Medicine – The Classics and the Health of the Soul” at 2017, Gallian, citing Italo Calvino’s “Why Read the Classics?”, explains that

[...] one of the most characteristic elements of a classic work is precisely that of presenting, in a masterful way, the ‘problem’ of the human as an eternal and universal issue, beyond historical and cultural circumstances. Thus, inevitably, reading a classic will lead to the recognition of these essential issues of human existence, arousing in the reader the curiosity and the desire to face them⁹. (p. 175-6)

In this sense, as a humanistic experience based on sharing reflections originated in literary works – therefore, an aesthetic-reflexive experience – LabHum makes participants articulate and express their affections, feelings and ideas, in a true transformative process that leads to an emotional renewal and to a new awareness, thus proving itself a powerful means of humanization¹⁰ (p. 13).

LabHum’s experiment shows that literature and literary narrative, in mobilizing affections, become an aesthetic event – of *aesthesis* (awakening) – in which this emotional awakening triggers an intense reflective process, by the immersion in and encounter with essential issues to human existence raised by literature.

Werner Jaeger, in his book “Paideia: the Formation of the Greek Man”, quoted by Gallian, had already said in the 1930s that



there is something at the heart of great works that has universal validity, and which, in some way, being recognized by those who are enjoying them, unleashes an emotional force capable of moving humankind. This experience does not have a merely sensible nature, but one of depth. It is not limited to an external dramatization that makes narrative become participatory, but goes into the spiritual, into that which the person has of most deep. And for the Greeks, this spiritual conversion, which is aroused by aesthetic experience and affects the person's ethical dimension, contains in itself the most profound and complete sense of therapy. Psychogagy is the conversion that brings healing, in its broadest dimension, involving spirit, soul and body⁹. (p. 200-1)

Jaeger's contemporary, Henri Bergson, at that same time, in his essay "The Perception of Change", highlighted the key role played by writers as artists of literature:

Art aims to show us, in nature and in spirit, outside and inside of us, things that did not explicitly impress our senses and our conscience. The poet and the novelist unveil that which was in us but which we ignored because our lack of words. [...] As they speak to us, nuances of emotion arise that could have been represented in us for a long time, but that remained invisible [...]¹¹. (p. 155)

It should also be noted what Paul Ricoeur says in his *Time and Narrative* trilogy¹². For him, the narrative mediates between language and action, having the property of apprehending the intensity of the human experience by inscribing it in temporality.

According to Ricoeur, narrating allows people the opportunity for establishing a more evident relationship with time, as it opens the possibility of learning about its passage, but also of announcing and sharing it, thus articulating the three great "instants" of existence – past, present and future.

Ricoeur also provides the conception of identity adopted in this study. According to him, this conception is always narrative in nature, as there is no way to understand it without resorting to narration. In the same way, it plays the role of mediator – as already mentioned – since it constitutes itself in the encounter with the other, allowing people to engage the world and change themselves, while remaining in the world.

It seems, therefore, that literary narratives, as artistic expressions, prove to be a vigorous means of possible personal transformations – and thus of humanization, as an expansion of "the sphere of the presence of being" – when used as tools for awakening and explaining affections, in a collective dynamics, in view of the possibility of reflecting on life and generating new meanings – based on perspectives and themes raised in literary books, as suggested by the Laboratory of Humanities.

As Antoine Compagnon points out in his book "What is Literature for?", literature, as the protagonist of this humanistic experience,



helps us gain access to a sensitive experience and to knowledge of morality which would be difficult, or even impossible, to obtain in the treatises of philosophers. It therefore makes an irreplaceable contribution to practical and speculative ethics¹³. (p. 46)

About the use of literature in the development of a hermeneutic approach to the health-disease relationship, Caprara says that

Literary works address aspects of human life, such as knowing how to deal with emotions, which are important constitutive elements especially in the doctor-patient relationship [...]
Communication between doctor and patient can be learned as a technique, but certainly the literary work allows building an ethical context in which this relationship goes on developing itself¹⁴. (p. 929)

Methodology

The methodology used in this study was that of the Laboratory of Humanities (LabHum), an activity of the research project Humanities, Narratives and Humanization in Health, of the Center for History and Philosophy of Health Sciences at the Federal University of São Paulo (CeHFi-Unifesp), which receives funding from Fapesp and brings together more than a dozen undergraduate (scientific initiation) and graduate (master's and PhD) researchers from the Collective Health and Health Sciences Teaching programs at Escola Paulista school of Medicine (EPM-Unifesp)¹⁵.

Created in meetings with undergraduate medical students, LabHum seeks to promote humanistic training and humanization in health¹⁶.

LabHum's methodology involves carrying out discussion cycles of specific books. Thus, each book reading is a cycle.

Regular cycles consist of weekly meetings, lasting one hour and thirty minutes.

Participants are expected to read the books before the start of each cycle, although this is not an activity exclusive to the participants.

At the first meeting, the activity coordinator tells LabHum's history, explains the objectives and methodology, mentions the possible effects to be achieved and clarifies the theoretical basis of the experience.

After this presentation, the activity begins by inviting the participants to report their Reading Stories – the first stage of the methodology. They should narrate their personal experience of reading the work, focusing on the affections awakened, feelings experienced, memories brought back and any doubts they might have.



After the Reading Stories stage, which closes the first meeting of the cycle, begins the Discussion Itineraries stage – the second stage of the methodology. This stage is focused on group reflections on the central themes of the narrative, as raised by the participants and recorded by the activity coordinator at the Reading Stories stage. The number of Discussion Itineraries' meetings varies according to the length of the book.

After completing the Discussion Itineraries, the participants experience the third and final stage of the methodology: the Stories of Living Together.

Narrated by the participants in a single meeting, these stories are individual syntheses of the experience of participating in LabHum's activities, either oral or written, sharing the effects of the experience on their lives and personalities.

If successful, this methodology can promote, at the end of its application, a review of values, concepts and opinions about themes important to human existence – thus fulfilling the expected humanization process.

Participant Observation and Oral Life Story were the research methodologies used.

The first requires, on the part of the observer, according to Valladares¹⁷, knowing how to see, listen, use all one's senses and ask questions at the right time.

With regard to Participant Observation, Fernandes¹⁸ says that it presupposes conviviality, communication and the exchange of experiences, mainly through the use of the senses, between the researcher, the study participants and the context of the relationships involving everyone – that is, it demands being present, observing, participating and taking notes while the actions take place.

Research data were collected through the following procedures: the activity coordinator makes an audio recording of the full meetings, of all cycles, using a smartphone audio recorder, and also takes field notes.

After the completion of the LabHum cycles, interviews were conducted with the participants according to the Oral Life Story technique¹⁹, namely: digital recording of the interview and its subsequent transcription, textualization, transcreation, verification and validation.

According to the authors, transcription is the rigorous transposition of recording into written text. Textualization, in turn, involves transporting and adding the questions to the answers, and the reports are reorganized in the first person. In transcreation, the researcher intervenes more actively, seeking to include in the text the feelings expressed during the story's narration. This transcribed version is subsequently submitted to evaluation, verification and to the authors of the narratives for their authorization, for validation and legitimization purposes.

After collection using the methodologies described above, the data was organized and interpreted, including through a qualitative approach, using the process of Immersion and Crystallization, developed by Miller and Crabtree and described by Borkan²⁰.

By performing consecutive readings of the text in order to experience it, this methodology involves rounds of immersion into the collected narratives. These rounds of immersion are followed by reflections by the researcher, which achieve what the author calls intuitive crystallizations of the data.



As it requires emotional and cognitive involvement, this method of analysis allows researchers to go beyond manifest interpretations to see, hear and feel the data, so that they may separate their own opinions from the discoveries and interpretations made.

After completing this first phase of narrative interpretation in a phenomenological perspective, emerging themes and categories were defined, which were subsequently examined in the light of the relevant theoretical framework to allow the presentation of considerations and conclusions that may guide new interventions in similar contexts and/or studies.

This study was approved by the Research Ethics Committee of the Paulista School of Medicine of the Federal University of São Paulo (EPM-Unifesp), registered under opinion no. 3,618,860.

Results and discussion

This study examined two LabHum cycles, conducted in October and November 2019 with two groups of ten women invited to voluntarily participate in the activity, all mothers of persons with disabilities aged between 8 and 16 years that are assisted by a non-governmental organization.

For both cycles, the narrative chosen was the short story *Um Apólogo*, by the Brazilian writer Machado de Assis.

Um Apólogo describes a fictitious dialogue, permeated by a high level of animosity, between a needle and a ball of thread, each excessively valuing its own work as the most important in the making of a dress and depreciating, as argument, the work performed by the interlocutor.

This narrative is a fable:

[...] short narrative, often identified as an apologue or a parable, due to the moral lesson, implicit or explicit, that it must contain, and to its dramatic structure. In general, its protagonists are irrational animals, whose behavior, while preserving their specific characteristics, is intended to allude, usually satirically or pedagogically, to human beings²¹. (p. 184)

This literary genre was chosen because it is written in a simple language and easy to understand, being accessible even to those who do not have the habit of reading, and also because it contains, implicitly or explicitly, inspiring messages and teachings, capable of having a positive impact on the thoughts and attitudes of those who, for various causes, sacrificed themselves in favor of a better life for their children.

The LabHum cycles discussing Machado de Assis' fable took place separately and comprised four meetings with each of the observed groups. These meetings were held weekly, covering the three phases of the LabHum's methodology.



To examine these LabHum cycles with the support of a pertinent bibliography, the following authors were used: Amiralian²², who analyzes how much the perception of another person's disability can raise awareness of one's own limitations and deficiencies, in addition to also addressing feelings, abilities and inabilities involved in the caregivers' empathy with the disabled person; Fédida²³, for ascribing to disability the resurgence of anxieties and for remembering the vulnerability of human beings; and Miller²⁴, who advises mothers, in particular, to adopt certain stress control practices for promoting self-care and, consequently, achieving greater balance in dealing with children with disabilities.

The experiment aimed to investigate the effects caused by the discussion of existential themes, raised by a literary classic, on mothers of people with disabilities, based on the assumption mentioned above that literature expands the capacity for perceiving experiences and the world, thus contributing to the reframing of feelings, values and experiences.

To fulfill the study's aims, the hypothesis tested was that the contact with adverse situations through literary narratives can generate empathy and allow the participants in the activity to share experiences and impressions about their personal difficulties in facing the limitations imposed by their children's disabilities, within the family, or about other aspects related to this situation from a broader social perspective.

During the execution of the cycles, considering the eight meetings held, 16 themes related to *Um Apólogo* were raised by the volunteers, listed below as mentioned:

1. arrogance/haughtiness;
2. pride;
3. vanity;
4. self-esteem;
5. maturity;
6. humility;
7. competitiveness;
8. envy;
9. alterity;
10. appearances;
11. sincerity;
12. adversities;
13. response to provocations;
14. empathy;
15. judgment; and
16. gratitude/recognition.



Some of these themes were discussed in depth, especially during the Discussion Itineraries meetings – the second stage of the LabHum’s methodology – and unfolded in perceptions and manifestations that allowed relating the core of this fictional dialogue between objects, in Machado de Assis’ short story, to unique aspects of the participants’ lives.

This relationship, between narrative and uniqueness, is, for Dilthey, a consequence of understanding in a hermeneutical approach, induced by literature as a means of objectifying subjectivity. Dilthey says:

The immeasurable importance of literature for our understanding of mental life and history lies here, in the fact that only in speech does the inner life of man find its complete, exhaustive and objectively intelligible expression. Therefore, the art of understanding has its centre in the exegesis or interpretation of the remains of human existence which contained in writing²⁵. (p. 367)

In this movement of connecting narrative with subjectivity, there was one theme among those raised during the LabHum cycles that was the most discussed and that emerged in both groups, although from relatively different perspectives: alterity.

In general, participants in one of the groups focused on the importance of other people in their lives and in collective efforts in favor of what they considered “a greater good,” as one of them said, instead of indulging in pride, vanity and competitiveness in the search of recognition, either by themselves or by others, as the needle and the thread did during their dialogue in *Um Apólogo*, resorting to mutual devaluation as a means of individual overvaluation.

Going back to Dilthey’s comprehensive method, Sass explains that taking such a position, as an interpretation of an experience, occurs when this interpretation is objectively expressed:

It is the objectified spirit of the human being that the comprehension aims to decipher. Comprehension only occurs through expression. And the meaning contained in the expression arises from the manifestation of what has been experienced in some way. Senses and meanings arising from experiences are thus interpreted²⁶. (p. 546)

In this sense, based on their subjective experiences and their interpretation of the fable, the participants expressed opinions and values about alterity – and related themes – using phrases such as:



- a. “we should pay attention to others”;
- b. “nobody is better than anybody”;
- c. “we need each other to evolve”;
- d. “alone, we are nobody”;
- e. “we depend on others for everything, from birth to death”;
- f. “what is the place of other people?”;
- g. “sometimes we just see our own qualities and not those of others. And everyone has both defects and qualities”;
- h. “we shouldn’t see the other’s defects as definitive. Not all piled-up stones are ruins”;
- i. “we should respect the opinion of others and know how to position ourselves in relation to them”;
- j. “I’ve learned to respect the point of view of others”;
- k. “why point the finger at others?”;
- l. “we have to learn to be proud of ourselves and of others too. After all, we are nothing without the others”;
- m. “each one learns from the other. We must not impose on others”;
- n. “I should not blame others for my problem”;
- o. “I try to put myself in the other’s shoes”;
- p. “living together is learning to respect and accept the other”;
- q. “I have to try and deal with other people’s differences”;
- r. “It’s not easy to deal with other people’s differences”;
- s. “I have to respect what the others are going through and their way of doing things”;
- t. “we are not isolated; we can’t achieve anything by ourselves”;
- u. “everyone plays an important role in creating the final product” [referring to the dress mentioned in the narrative]; and
- v. “each of us has our own qualities and our own individual mission, but we all depend on the other. All these qualities put together will achieve the expected result.”

Contrary to the reflections about this theme, but clearly expressing a subjective resignification of disability motivated by the collective reflection raised by Machado de Assis’ narrative, one of the participants declared that “special motherhood is a learning experience” and that “we need to love each other first [before loving the other],” thus evidencing that before the other there is a self that needs to be perceived, respected and valued, whatever its condition.

Regarding this relational perspective, between the self (represented by the mother) and the you (represented by the other idealized by her), for the construction of alterity, Buber says that



Only he who himself turns to the other human being and opens himself to him receives the world in him. Only the being whose otherness, accepted by my being, lives and faces me in the whole compression of existence, brings the radiance of eternity to me. Only when two say to one another with all that they are, “It is *Thou*”, is the indwelling of the Present Being between them²⁷. (p. 65)

Disability from the perspective of alterity

If the participants in one of the groups focused their reflections about alterity on an attempt to equate people’s conditions, regardless of having disabilities or not, even if under the single and limited perspective of the importance of the collective in building a more equitable reality – in analogy to the fable’s dress being made by the needle and thread (and by other characters, secondary and/or not mentioned) – the second group attempted to formulate a theory, but not scientific, based on the role played by the protagonists of the story and on their dialogue.

In analogy to the task of “leading the way” performed by the needle in the narrative, one of the participants declared that she thought it was “cool” for the needle to “going on leading the way” for the thread to sew the fabric that would become the dress. And she completed her reasoning by asking: “How many times do we lead the way for other people, and the reverse too?”

This considerations led to a collective observation, based on a subjective perception common to all participants, about disability: although families today still have to face stigmatized views of disabilities – and, as one of them declared, “there is difficulty in accepting the people as they are” – our current society, in general, is more inclusive compared to that of other times. And this only happened, according to these women, because “many people has led the way for us to get here,” as another participant said, recalling the role played by the needle in Machado de Assis’ apologue.

This taking up of a passage of the narrative by the LabHum’s participants, after this observation, led another mother present to say something that translated an affection aroused in the whole group during the meetings: “In fact, today’s mothers and their special children are the needles for the new generations, leading the way for deeper social transformations, for the construction of a new society.”

This opinion led two other participants to comment in the same vein.

The first declared that “being a needle is an honor, because the important thing is to lead the way for others. But we are also threads, following the lead of other needles.” The second, in turn, admitted that “what I want to be in life is a needle and lead the way for other people.”

In the process of reframing filial disability and “special maternity” during LabHum’s activities, both issues frequently emerged, whether or not the topic of alterity was being discussed. It was possible to observe, however, that sometimes they appeared as expressions of subjectivity, while at other times they came up as almost didactic expositions of the problem.

Three of these passages, by different participants, deserve to be highlighted:

1. One participant disapproved of the term “special people” for people with disabilities, arguing that “special people are not people, but their needs” – in reflecting on the place of the other as a person with disabilities, in a society not yet fully inclusive;
2. Another commented on how transformative the experience of having a child with a disability is, admitting: “I changed after having my special daughter. And I am proud of the person I am today” – regarding reflections on pride, in analogy to the way this feeling was explored in Machado de Assis’ narrative, from the perspective of the needle in relation to the thread;
3. Yet another addressed the way in which society perceives “special mothers.” According to her, “the special mother is always being judged. When she is with her son, she is a warrior, a good person. But when she is not with her son, who needs her, she becomes a bad person and stops being regarded as a good mother” – regarding the question of judgment, addressed in *Um Apólogo* from the perspective of the thread, which accused the needle of having a “low and humble” role in the making of the dress.

These comments show the externalization of the self of these women, with respect to what they represent in relation to and in virtue of the other, fostered by the elaboration of the themes raised by a literary work.

Regarding the question of alterity in the passages 2 and 3 mentioned above, Paul Ricoeur explains that “The self-designation of the speaking subject is produced in interlocutory situations where the reflexivity is combined with otherness [...]”²⁸ (p. 111) and that “[...] the alterity of the other person, like all other alterity, is constituted *in me* and starting from (aus) me [...]”²⁸ (p. 169).

Lévinas, in turn, in his analysis of the role of discourse and language in his formulations about the same theme, explains that

Through discourse, exteriority manifests itself without any violence and the self is placed in relation to a totality that, going beyond subjective existence, realizes the encounter between two beings, a self and a you. However, this self and this you that appear in the face to face of the discourse are roles played in the social drama, as the interlocutors are determined by different conditions²⁹. (p. 45)

However, if the literary work promoted an awakening of affections and speech-language allowed the expression of viewed by these women as a plausible reality through the relationship formed in that encounter.

If the perception presented here resulted from the recognition of people with disabilities and their caregiver-mothers as others co-responsible for building a longed-for new sociocultural order, more inclusive and less discriminatory, we can thus argue that Machado de Assis’ fable, within the context of the discussions held during LabHum’s meetings, fulfilled an important role of reframing values and re-elaborating desires, as expected from a humanistic experience.



Final considerations

The high level of subjectivity perceived in the comments of the participants in the LabHum cycles, combined with the theoretical frameworks that guide the application of the methodology, allows us to conclude that this activity can be a tool to promote the reframing of opinions, values and concepts, in an experience of self-knowledge and knowledge of the other.

This, as seen, is indeed a humanistic approach, since it impacts, based on a process of awakening by art, three essential dimensions of existence: affection (which, in LabHum's experience, derives from an individual reading of the literary work), intelligence (manifested in reflections on the themes raised by the narrative) and will (expressed in the way the effects of the experience affect the *ethos* of the participants, leading to a process of humanization).

In summary, the Laboratory of Humanities uses the aesthetic to access the ethical – sometimes even remodeling it – enabling, in an experience of meeting with the other, the opening of new perspectives, capable of promoting personal and collective changes, in private and/or professional life.

As Compagnon says in “What is Literature for?”, when he argues that “literature frees us from our conventional ways of thinking about life – ours own life and that of others”¹³ (p. 50) and that literature’s “emancipating power [...] will at times make us feel like bringing down idols and changing the world. However, most of the time it will simply make us more sensitive and wiser; in a word, better”¹³ (p. 50-1), LabHum's experience with mothers of people with disabilities contributed, effectively, to the emergence of a more humanized and less stigmatized view of disability, of the socio-emotional impacts imposed by disability – and on them – and of the very role they play in society, as co-responsible for promoting inclusion actions, practices, measures, strategies and policies capable of situating their children no longer in a condition of exceptionality, which should receive a differentiated treatment, but as part of a new, equitable, non-discriminatory and more humanized reality.

Authors' contributions

All authors actively participated in all stages of preparing the manuscript.

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Este estudo tem como objetivo demonstrar os impactos da literatura em mães de pessoas com deficiência, no que concerne à ressignificação da condição de “mães especiais”, por meio de participação na atividade Laboratório de Humanidades (LabHum), do Centro de História e Filosofia das Ciências da Saúde da Universidade Federal de São Paulo, Brasil, cujos propósitos são despertar afetos e sentimentos e fomentar a humanização pela discussão coletiva de temas existenciais suscitados nos clássicos da literatura universal. O estudo foi desenvolvido sob três metodologias qualitativas após leitura individualizada da fábula “Um apólogo”, de Machado de Assis: do próprio LabHum, História Oral de Vida e Observação Participante. Os resultados indicam transformações positivas de perspectivas e reelaboração de valores humanísticos acerca do papel que essas mulheres cumprem como cidadãs que buscam ampliar o debate sobre a inclusão de pessoas com deficiência na sociedade.

Palavras-chave: Deficiência. Humanização. Laboratório de Humanidades. Literatura.

El objetivo de este estudio es demostrar los impactos de la literatura en madres de personas con discapacidad, en lo que concierne a la resignificación de la condición de “madres especiales”, a partir de su participación en la actividad Laboratorio de Humanidades, del Centro de Historia y Filosofía de las ciencias de la Salud de la Universidad Federal de São Paulo, cuyos propósitos son despertar afectos y sentimientos y fomentar la humanización, por la discusión colectiva de temas existenciales suscitados en los clásicos de la literatura universal. El estudio se desarrolló bajo tres metodologías cualitativas, después de la lectura individualizada de la fábula “Um Apólogo”, de Machado de Assis: del propio LabHum, Historia Oral de Vida y Observación Participante. Los resultados indican transformaciones positivas de perspectiva y reelaboración de valores humanísticos sobre el papel que esas mujeres cumplen como ciudadanas que buscan ampliar el debate sobre la inclusión de personas con discapacidad en la sociedad.

Palabras clave: Deficiencia. Humanización. Laboratorio de Humanidades. Literatura.