



Revista Bioética

ISSN: 1983-8042

ISSN: 1983-8034

Conselho Federal de Medicina

Wagner, Valdilene; Garcia, Lucas França; Lucena,
Tiago Franklin Rodrigues; Oliveira, Leonardo Pestillo de
Sintagma identidade-metamorfose-emancipação na trajetória da pessoa com deficiência
Revista Bioética, vol. 28, no. 1, 2020, January-March, pp. 24-33
Conselho Federal de Medicina

DOI: <https://doi.org/10.1590/1983-80422020281363>

Available in: <https://www.redalyc.org/articulo.oa?id=361570650004>

- How to cite
- Complete issue
- More information about this article
- Journal's webpage in redalyc.org

UABM
redalyc.org

Scientific Information System Redalyc

Network of Scientific Journals from Latin America and the Caribbean, Spain and
Portugal

Project academic non-profit, developed under the open access initiative



UPDATE

The identity-metamorphosis-emancipation syntagm in people with disabilities

Valdilene Wagner¹, Lucas França Garcia¹, Tiago Franklin Rodrigues Lucena², Leonardo Pestillo de Oliveira²

1. Programa de Pós-Graduação em Promoção da Saúde, Centro Universitário de Maringá (Unicesumar), Maringá/PR, Brasil.
2. Departamento de Fundamentos da Educação, Centro de Ciências Humanas Letras e Artes, Universidade Estadual de Maringá (UEM), Maringá/PR, Brasil.

Abstract

Worldwide, one in seven people have disabilities. In order for them to achieve emancipation, it is essential that their identity is recognized. This was a qualitative, descriptive study based on the analysis of oral reports regarding the life trajectory of a physically disabled person. Affected by post-poliomyelitis syndrome and relying on a wheelchair, this person is understood here as an emblematic subject. Our goal was to use this narrative as a means of understanding how one's environment builds an identity and produces emancipatory metamorphoses. The identity-metamorphosis-emancipation syntagm was chosen as a theoretical apparatus. Our results revealed several aspects of the individual's life, discussed separately and structured in a timeline to facilitate data visualization and analysis. Although the subject has assumed several personas during her life trajectory, she is unable to emancipate herself due to the maintenance of certain stigma-reproducing structures that make it difficult – or even impossible – for her to recognize her identity.

Keywords: Disabled persons. Personal autonomy. Social stigma.

Resumen

Sintagma identidad-metamorfosis-emancipación en la trayectoria de la persona con discapacidad

Una de cada siete personas en el mundo tiene alguna discapacidad y, para que puedan emanciparse, es fundamental que se reconozca su identidad. Este estudio cualitativo de carácter descriptivo se basó en el método del relato oral de la vida de una persona con discapacidad física, acometida de síndrome postpolio, usuaria de silla de ruedas, entendida aquí como sujeto emblemático. El objetivo fue entender, mediante su narrativa, la manera en que el entorno construye la identidad y produce metamorfosis emancipatorias. Como aparato teórico, se utilizó el sintagma identidad-metamorfosis-emancipación. Los resultados revelaron varios aspectos de la vida del individuo, los cuales se discutieron por separado y se estructuraron en una línea del tiempo para facilitar la visualización y el análisis de los datos. Por tanto, a pesar de asumir diversos personajes durante la vida, el sujeto emblemático no logra emanciparse debido al mantenimiento de determinadas estructuras reproductoras de estigmas que dificultan e incluso imposibilitan el reconocimiento de su identidad.

Palabras clave: Personas con discapacidad. Autonomía personal. Estigma social.

Resumo

Sintagma identidade-metamorfose-emancipação na trajetória da pessoa com deficiência

Uma em cada sete pessoas no mundo tem alguma deficiência, e para que possam se emancipar é fundamental que sua identidade seja reconhecida. Este estudo qualitativo de caráter descritivo baseou-se no método de análise do relato oral da vida de uma pessoa com deficiência física, acometida por síndrome pós-poliomielite, em cadeira de rodas, entendida aqui como sujeito emblemático. O objetivo foi entender pela narrativa como o ambiente constrói a identidade e produz metamorfoses emancipatórias. Como aparato teórico, utilizou-se o sintagma identidade-metamorfose-emancipação. Os resultados revelaram vários aspectos da vida do indivíduo, que foram discutidos separadamente e estruturados em linha do tempo para facilitar a visualização e análise dos dados. Portanto, apesar de assumir diversos personagens durante a vida, o sujeito emblemático não consegue emancipar-se devido à manutenção de determinadas estruturas reprodutoras de estigmas que dificultam ou até mesmo impossibilitam o reconhecimento de sua identidade.

Palavras-chave: Pessoas com deficiência. Autonomia pessoal. Estigma social.

The authors declare no conflict of interest.

About one billion people live with some type of disability. Considering the extension of life expectancy, the consequent global increase in the incidence of chronic diseases, and the occurrence of accidents, disasters and conflicts, this number should grow even further in the coming years¹. Approximately 70 million people worldwide require assistive technologies such as wheelchairs, but only 5% to 15%², on average, have access to this resource. Accessibility facilitates the use of health services and alleviates inequalities, while providing social inclusion, health promotion, and reducing avoidable injustices³.

The political struggle to reduce inequalities affecting these vulnerable groups is interlinked with the active search for emancipation and citizenship rights. These are supported by legislative devices such as Law 13.146/2015⁴, known as the Brazilian Law for the Inclusion of People with Disabilities. However, these mobilizations are not free from contradictions and practical challenges, and often end up leading to disillusionment, placing obstacles in the way of the establishment of relationships marked by a genuine sense of belonging^{5,6}.

Thus, in addition to seeking rights, it is necessary to reflect on how society has consolidated them. In order to do that, it is necessary to understand how the disabled person's identity is constructed. In this study, identity-building is seen as a process of metamorphosis, based on the identity-metamorphosis-emancipation syntagm. According to critical social psychology's definition of this concept, identity is in constant transformation, and subjects are both authors and characters (or personas), building their own identities in the social movements of a historical period⁷.

This theoretical approach allows individual aspects to be dialectically put into a broader social, political, economic, and historical context. It describes the self-production of a person through the life-death-life process – i.e., the being's transformation, which ultimately leads to a state of awareness of the conditions underlying one's existence, and thus to a desire for emancipation⁷.

In this sense, identity is understood as human metamorphosis, potentially impelling the subject towards autonomy and the achievement of emancipation. However, although this process entails the composition of several personas throughout one's life trajectory – structuring them according to different modes of identity creation – it does not ensure autonomy, a precondition for effective metamorphosis and emancipation. This occurs due to the subject's historical and material

construction, which is influenced by economic, symbolic, intellectual and cultural capital⁷.

From this perspective, to achieve emancipation, the subject must experience a movement of change. As life's events are experienced, the being's transformations surpass their extrinsic character and become forms of self-determination arising from intrinsic motivations. These motivations lead the subject to strive to *be*, to play a role in the world, to become an agent, therefore acting as a driving force of identity-building metamorphoses⁷.

Considering the multifarious discourse on accessibility and law-supported rights, it is worth asking what prevents this group of people from effectively establishing a relationship of belonging to spaces in which they would be able to interact with other diverse groups and relate to other human persons – who, like them, share history-forming feelings and experiences that build them as beings in the world. Thus, this study aims to analyze how one's environment forms the identity of a physically disabled, wheelchair-ridden person, producing emancipatory metamorphoses. Consequently, it does not focus on the dimension of accessibility, which addresses different types of barriers as access-preventing objects. Despite the importance of the abovementioned discussions, this analysis focuses on the subject's self-determination, their relationships of belonging and their search for autonomy, based on the identity-metamorphosis-emancipation syntagm⁷.

Method

This was qualitative-descriptive research based on the oral account of the life trajectory of a physically disabled wheelchair user. It examines the narrative evocation of memory as a means for the transmission of life experiences, in order to understand how the environment constructs identity, producing emancipatory metamorphoses⁸. Oral history has a specific documental nature, conditioning the questions asked by the researcher and demanding an approach that is relevant to the researched subject⁹. This method allows extracting analytical categories from individuals' discourse while avoiding the devaluation of the meanings participants attribute to their own lives. In this sense, the only guiding question is: "Who is [person's name]?"

Interviews were conducted by a researcher with an academic background in the fields of physical education, pedagogy, special education, and health promotion. The analysis of the interviews was based

on the identity-metamorphosis-emancipation syntagm developed by Ciampa⁷. Supported by the theory of self-determination⁵, it aimed to understand how identity is built through stable bonds that connect people to each other, addressing the basic psychological need for belonging as a potential path towards emancipation.

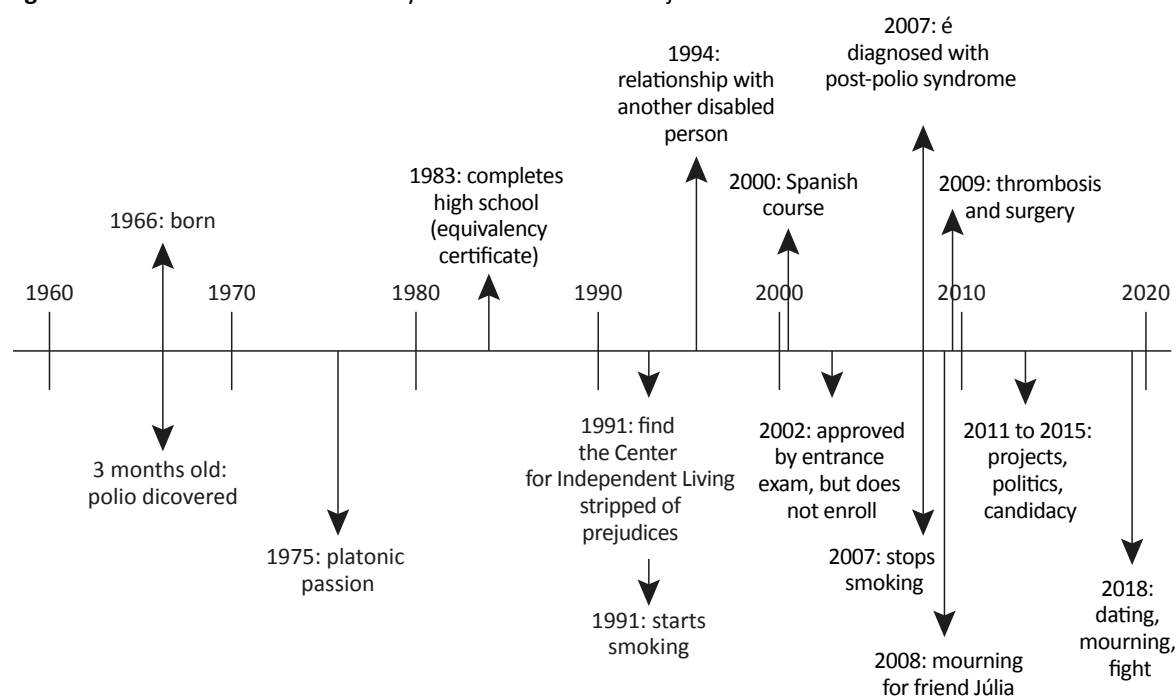
The research subject was chosen according to the typology by Griebeler¹⁰, in which the participant is treated as an emblematic subject whose identity is built on the basis of her/his relationships with others. One participant was randomly selected, via convenience sampling, among a focus group developed for studies that had been previously carried out by the researchers. The participant was initially approached by phone, and then received the researcher at home on two occasions: the first for an interview, which took place in the afternoon and lasted five hours, and the second for interview validation (also in the afternoon, for three and a half hours). The data were recorded in audio format and later transcribed, verbatim, for analysis. At the

second meeting, the interview transcript was read, the participant agreed with the recorded data and pointed out that there was nothing to add.

Results

The interviewee is a 52-year-old woman who will be identified here by the fictitious name of “Laila”. She is unemployed, receives welfare assistance and her disability is classified as tetraparesis due to infantile paralysis. She is entirely dependent on caregivers and the use of a wheelchair. Figure 1 outlines the reported facts chronologically, prioritizing those she emphasized the most during the interview. This timeline made it possible to group parts of her history under the following themes: diagnoses and educational trajectory; friendships and rejections – social relationships, political life, romance, the beauty of being who you are, and the communicative dimension.

Figure 1. Timeline of the oral life story of the emblematic subject Laila



Diagnostics and school trajectory

At 90 days of age, Laila was afflicted with a severe fever of unknown cause. After several hospital admissions, the doctors discovered she was tetraparetic by infantile paralysis. She had no strength and was unable to execute any kind of movement. Years later, both mother and aunt went far and beyond to enroll

Laila in school, but due to strong paternal opposition, her insertion was late: *“My father didn’t want me to study because he thought I was going to suffer what is now called bullying, right? He thought there was going to be prejudice and such, but there was none of that. In fact, I think a bit of the prejudice actually came from him, since prejudice starts in the family, right?”* (Laila).

Together with her neighbor, she managed to take part in catechesis. It was a way to enter the school environment. She has a deep admiration for her teacher. Lacking hand coordination, Laila learned to write at the age of 11 by putting the pencil in her mouth: *"I went on, adapting however I could. In the beginning I was mostly eating pencil... Holy Mary! Bloody hell."* Using the mouth to write impaired her vision, and she now has to use three-dimensional lenses (for short, medium and long range).

In adolescence, she considered herself a rebel. She stopped studying in the 7th grade and took a high-school equivalency course at the age of 18. She smoked from 25 to 41 years old: *"I started smoking in secret... you know that thing about forbidden fruits tasting better."* She stopped because *"there was no fun in it anymore."* She took four university-entrance preparatory courses and used to miss some classes to talk and smoke with other people: *"I did what I wanted to do, but I do regret it. I'm not a university graduate today, and it's not for lack of opportunity, no... It's because I had a lot of fun, partied a lot."*

At one time, during one of her regular physical therapy activities, she felt a overwhelming weakness in her limbs, especially the arms, which already had a limited range of motion. When she was first diagnosed during childhood, polio had already spread throughout her body. The second diagnosis came after the age of 40: *"The tests revealed 98.9% of my neurons had died. I looked at the neurologist and said: 'Damn! I'm dead. How terrible! I'm feeling nothing'. It was confirmed, then, that I had an (old) new disease. I had already had childhood paralysis during childhood, and what I have today is its development – post-polio. The second stage came to destroy what had not been destroyed the first time: that's why I can't move this arm and this leg. I can move my left foot a little, and my right hand."*

During the same period, she was diagnosed with thrombosis, and had to undergo emergency surgery. Her post-operative hospital stay lasted for three months, and she suffered severe bleeding, triggering anemia. Amputation was her biggest fear: *"The idea of losing a member is very present for me. It would be a tragedy to amputate anything, because destiny has already deprived me of so much."*

Friendships and rejections: social relations

During her youth Laila made a group of non-disabled friends, and kept a busy social life at their side. She remembers this phase of her life with nostalgia, characterizes it as a great period and says

that she did things she does not regret. Until she was about 25 years old, Laila avoided relationships with disabled people: *"I was prejudiced. I would not accept another wheelchair user near me. When we were going out to party, right? In the past, it was the going-out-to-dance thing. And when someone said to me, 'Look, there's a wheelchair user there!' I would reply: 'Don't even tell me, 'cause I don't want to go near them.' You know? This kind of malice? Because it was a really cruel thing."*

Over time, the group of friends grew apart: some got married and others went to live in distant cities. Laila went on to stay at home and her life started to change again. Her mother and a friend insisted that she join a community association. She was received by a man who had been in a wheelchair for four months: *"Wow, I took it like a kind of veiled attack, you know? Tuff! Okay! He politely pointed me towards a kind of knowledge that I had been unable to learn in 20-something years in the chair. I did not know the slightest about what he had told me. I felt ashamed. I thought: 'That's why I'm suffering, because I don't accept my condition even though I have been in it since I was 3 months old'"*.

Near this man, she realized that her behavior was too polarized and inconsistent with her condition, and began to strive to accept who she really was: *"My life started changing, changing; I know I still have a lot to change, we only stop learning when we die. Which is natural, right? This man was really my master, so I often tell him: 'You are my inspiring muse.' My life started changing radically."*

At the community center, she learned that she could have an independent life – the fact that she needed someone's help in order to get out of the wheelchair would not prevent her from making choices. Laila says she does not care what others think about her. She enjoys having an autonomous life, claiming to possess self-determination to come and go as she pleases. Respecting her own limits, she travels all over the city using public transport. She is saddened by disabled friends who stay at home because they are ashamed to face people's judgment: *"You can look at me sideways: I don't care, I am indeed crooked. To hell with it! I say to her [the friend]: 'Look at your own beauty! And don't fret.' And I fight with her. Because the place where she exchanges the chair's battery is three or four blocks away from her house, and she has to go with someone. I said: 'You seem like a retard, do I have to hold your hand and take you? A woman that size?'"*

Laila suffered the loss of a friend, referred to in this study by the fictitious name "Júlia." Júlia was

another wheelchair user, and died unexpectedly nine years ago. She had post-polio and her condition suddenly worsened: *"I called her, and she was in a real bad way, so I went over to her house. When I got there, she was lying on a mattress on the floor. I said: 'Júlia, what is this?' Right? It was a real punch in the face to me, that thing. She looked like a kitten, you know? Everything was like, the little pot with water or milk, drinking with a straw."*

Laila narrates how she had tried to encourage Júlia, taking her to parties and barbecues against the will and fervor of Júlias' religious family. Laila's extroversive impulse led to several conflicts between her and her friend's father. She also tried to encourage Júlia to study: *"'Julia, let's study!'"* [Laila encouraged]. *'Me, why? I'll get the diploma and throw it in the drawer!'* [replied Júlia]. *'So? At least you'll know how to talk in the social circles; you're smart, take advantage of what you have...'* [Laila replied]. *'Not me'* [Júlia refused].

Laila went through 11 university entrance exams, stopped trying and did the 12th after 17 years. She was approved in a private institution, but did not enroll because she was unable to get a full scholarship. She stresses that the life of a person in a wheelchair is very expensive. During the hiatus period, she dedicated herself to a Spanish course, completed in four years.

Her degree of self-determination during this period shows that at this stage in her life she tried to emancipate herself, and in this context there is a great need to belong to a social group. Laila's intrinsic motivation made her want to learn to coexist, partake in and interact with the world, as a socially active and capable human being. Despite the immense difficulties caused by external factors and the environment, which hinder access to higher education, Laila believes that people with disabilities should *"work with what they have."* Laila was unable to access the means to develop the skills that would allow her to compete in equal footing – so how could she emancipate herself?

Political life

Laila started to fight for rightful spaces for people with disabilities. She developed a project entitled *"Sentindo na pele"*, (*Feeling in the skin*) in which city councilors would be invited to move around public spaces using wheelchairs. The project intended to subject councilors to a practical experience that would lead them to take a stand against architectural barriers, creating projects in favor of accessibility.

During the experience, the councilors complained a lot about the discomfort in the chair, pain in the arms, and difficulties to climb ramps. The chair that Laila uses was obtained from the Unified Health System: *"I don't like the term 'to win' [as in obtaining something for free]. This [taps her hand on the chair's support] has been more than paid by taxes."* Since she was unable to obtain practical answers from parliamentarians in terms of improving accessibility in the municipality, she ran for councilor, but was not elected.

In addition, she remained in solidarity with friends when it was necessary to resolve issues of a public nature, as in the case of a conflict around transportation for people with disabilities: *"They would get the passengers at 2 pm, so these passengers would spend the entire day walking around. And then they would leave the person at the door of the State Basic Education Center for Youth and Adults only at 6 pm. This is absurd!"*. The conflict motivated a group of transport users to gather, find the responsible party and expose this and other complaints. The act led to the dismissal of an employee and improved the service's routine.

Romance

Laila's narrative puts great emphasis on her relationships and how much she would like to have someone to share life's moments with. She makes her feelings about loneliness and her longing for company very clear. When she was between 23 and 24 years old, she fell in love with a friend: *"Prejudice was very marked at the time, and he didn't have a disability, he doesn't. I felt prejudice on his part or maybe on my part, because I was like that. But then I think: did I really love him or was I just being needy? We have to go through each of these phases. I don't know if the next is better or worse than the previous one, but, anyway, that's what we're here for."*

Later, when she had been able to overcome the barriers of prejudice, she fell in love with a visually impaired person: *"My relationship with the blind boy was an entire year of comings and goings. I was about 28 and thought I was dating, but he threw a figurative bucket of ice water at me. Said it wasn't really dating. I think I got kind of traumatized from that. I never really had a boyfriend – at least not the kind that comes home with you"* (Laila).

Laila was thrilled to talk about a 54-year-old man with polio who she had recently met in a WhatsApp group: *"I thought he was really cool... The guy even (...) One person was making moves on the other without knowing it, until it finally came out. He said: 'Look, I'm going to make a request, but you*

have until the afternoon to answer, you have until the afternoon to think about it carefully.' I said 'wow, what is he going to say?' And then he said: 'Do you want to be my girlfriend?' Oh my God! Right?!".

She accepted. He lived in another city and the two spent 15 days chatting online and making plans to visit each other: *"We even had anniversaries in the same month. It was really like that, you know? I said 'wow! I found my better half.' And I told him this, and he said, 'I think I found mine too.' Because everything fit so well, it was so beautiful, so cool; I would never have been able to imagine an ending like this, never!"*

After the first 15 days of intense conversations, he left the social network. When Laila called, she found out that he had been admitted to a hospital, due to complications from appendicitis. Moaning from pain, he talked to Laila. They said goodbye. He passed away the following day: *"Last night, it's even registered there, nobody touched his cell phone, nobody, but I got a cellphone warning, you know, that 'I'm available' notification? It arrived. I went in there, nobody had touched his device. Heavenly father! I said 'Guys, what is this?' When I saw that, you know, in that moment... I thought 'I'm going to talk to him, I'm going to talk to him'... But he is not alive anymore! Because there's a lot stuck in my throat, not due to malice nor fighting, but I had a lot of things stuck in my throat, things that had to be said, and now I know I won't have the chance any more."*

After a few moments in silence, she said: *"Then I feel this emptiness, you know? During those days we talked a lot, like a lot, really a lot, I can't even explain what that was. It was a very fast meteor that completely transformed my life. And suddenly, his suffering prevailed. And then... it was over."*

The beauty of being oneself and the communicative dimension

Given all the situations she experienced, Laila admits that she sometimes was successful and sometimes failed. She takes on a strong personality and a combative stance: *"It's not that I used to fight, I don't think it's a fight, but I don't know what else to call it. Could I be a warrior? Beats me... It's possible I'm being too pretentious, but I've always liked these things, you know? Not as a politician, I hate that stuff, but unfortunately we depend on it, right?"*

She describes herself as a warrior, a soldier. Her self-perception comes from her struggles and political identity, whether in the context of the struggle for life or between health and illness, or in the context of the struggle for fundamental rights

and for recognition in a relationship or in the eyes of society. Her personas are fighters forged in an individuality that strives for autonomy, and whose most urgent desire is emancipation: *"This is how I see it: I don't care about my physical appearance, I really don't. I get ready, I go out and I don't care what society thinks, no. I've never cared. Never, because I think this is like a habit, right? A family thing. Because I think my parents never tried to hide me, as people used to do, say, 50, 70 years ago. Sometimes the person died and even the neighbor had no idea there was a disabled person in there, and so I think that's why I was never hidden."*

This account exposes the relationship between stigmatized people and "normal" people in the processes of social interaction, not only for Laila's individual reality, but also from a historical perspective, considering the social negation of people with disabilities: *"So Laila is not a failed woman, she is a disappointed woman – I fight. I feel like a warrior, but I do need support, and I don't have it. Support in every way, because a swallow does not make summer. We need more unity, and this is something nobody has... This is the only missing piece of the puzzle, because if everyone came together for one cause, it would be so much easier (...) More unity between everyone is all I ever wanted"* (Laila).

This aspect of her story shows how identity policies produce social practices that result in the maintenance of stagnant identity types. As much as subjects strive to overcome certain situations, they are imprisoned and unable to fully fulfill themselves as human beings. However, as time went by, Laila was able to transform herself through the different personas she took on – metamorphoses that enabled new life directions, resignifying the past and the way she saw herself: *"We take a lot of blows, and I never had a lot of hesitation when speaking my mind, so communication for me is very important, it is fundamental. And here I am! Through communication I will manifest myself, because if I rely on my appearance, nobody will really care."*

Discussion

Diagnostics and school trajectory

The attempt to extinguish polio is a strategic plan of the Global Polio Eradication Initiative (GPEI). Currently, new cases are diagnosed only in Afghanistan and Pakistan¹¹. The World Health Organization (WHO)¹ and the Pan American Health Organization (PAHO)¹² intended to eradicate all types of poliovirus

by 2018¹³. Despite improvements, however, the disease remains active.

After polio is diagnosed, families deal with feelings of denial, sadness, resignation, revolt, making acceptance difficult and leading to a constant search for the fabled cure¹⁴. These feelings are observed in Laila's trajectory, whose childhood transformations became part of her identity.

In elementary school, her teacher played an essential role, by creating a fruitful study environment. The encouragement of positive experiences in the school environment enabled the interviewee to establish affectionate relationships with knowledge, a fundamental and indispensable factor in learning. As an educator, this teacher influenced her beyond the walls of the school, building a deep affective bond between the two.

Affection in the school environment is an extrinsic motivation that, together with intrinsic factors, such as curiosity and personal values, is fundamental for children and adolescents's permanence in school⁵. People become educators by vocation and teachers by profession, and every vocation is born out of love and hope. These feelings are often misunderstood by the dynamics of educational institutions. In the teacher-student relationship, however, they allow barriers to be transcended, promoting individual emancipation¹⁵.

Adolescence's inherently transitional character causes behavioral changes, during a phase defined by the attempt to establish oneself as a being in the world. Adolescence can be understood according to three aspects: the biological, encompassing puberty and bodily changes; the psychoanalytic, i.e., going through the contrasts and contradictions of adolescence; and the sociological, which considers the social traversal of the subject towards autonomy, until maturity¹⁶.

In the case of people with severe physical disabilities, puberty – a developmental period for the body – can entail the affixation of vulnerability to social constructs. In Laila's case, the body is seen according to a social risk perspective. This risk was attributed to her by the members of her family, such as when her father tried to limit her social life. Despite this, she tried to establish herself during adolescence, in the context of affective aspirations and bonds with different groups. Thus, driven by a desire for affirmation and social recognition, she preferred to communicate and interact with several people. When she had time to dedicate to her studies, she ended up rebelling, reproducing

transgressive habits, such as lying to her family and smoking, in order to rid herself of social isolation¹⁶.

Her attempt to be recognized among certain social groups can be likened to her construction of political identity. By means of the desired recognition, she sought to transform personal traits through communication, pursuing autonomy – this time in the political context¹⁷. The conflict between education, health and illness has been constant. However, Laila is not only a biological, but also a social being. Life's dynamics permeate her relations with the world and transform her continuously, making her a different person every day. In this way, her actions are not ends in themselves. She cannot be regarded as a pure abstract consciousness forged in subjectivity, nor can she be reduced to the condition of a thing forged by the objectivity of biological and material facts. On the contrary, to make sense of human existence, one must consider the dialectical movement within this dualism¹⁸.

Friendships and rejections: social relations

Laila went through a complete metamorphosis, starting from self-denial, going through denial of other people with disabilities, and arriving at self-acceptance, acceptance of the other, and immersion in the previously rejected social group. The prejudiced Laila became altruistic, empathetic and self-determined, i.e., what she "*really was*." The dialectical overcoming of this contradiction gives rise to a new, metamorphosed persona, a third being that is a synthesis of both¹⁸.

For her, learning is an opportunity to overcome, showing that she can be more than someone with a disability: it means being regarded as a thinking person, a rational, critical person, who can and must be recognized. It also represents an opening for coexistence with other groups, for being able to interact socially, talking about any subject in any social field, including the job market.

The forms of domination that involve people with disabilities segregate and hamper the consolidation of social rights. Despite the immense effort to overcome oppression, the identities of this group remain unrecognized, and thus they are reduced to the status of marginalized categories. Laila's struggle to assert her identity is similar to that of people who seek to transform identity politics into political identity. This process is only possible through emancipation¹⁹.

In an attempt to relate the categories language and work, Habermas²⁰ attempts to explain language as a necessary component for the completion of

the subject's hominization. Critical discussions on the scientific method approach the transformation of man through work, regarded as a model for all human activities²¹. Laila strives to join the job market by repeatedly attempting to enter a higher education course: she desires to become a professional. Facing the barriers in this process, she completes a Spanish course and starts to teach unpaid classes for people with disabilities. Thus, it appears that communication was the strategy she employed to build her place of speech and interact socially.

This desire to enter the job market is related to the struggle for recognition and the need to belong. She uses communication to establish herself as a professional, but is unable to enter the formal world of production. Access to higher education would have been her attempt to build herself as a human being through work²⁰.

The relationships she produces between work and language allow her to place herself in the shoes of different personas: student, friend, Spanish teacher. However, she is unable to achieve the aspired emancipation, since her work does not lead to material (financial) results. The demands of a society based on the production of material goods are justified by the transformation of nature required to maintain the capitalist system. In this context, it is clear that Laila's success in becoming an independent person does not fully meet her own expectations of emancipation.

Ciampa warns that *metamorphosis, even when prevented, even when obfuscated, is still an expression of the invincibility of the human substance as a historical and material production*²². This sheds light on other factors behind the construction of Laila's identity. Her great transformation – the acceptance of other people with disabilities and the establishment of ties with them (going so far as making them the main pillar of her support network, at a time of great anguish and mourning) – shows how much her identity has changed over time and throughout the spaces in which she lived. Identity does not remain the same, because it is forged every day, under specific historical and social conditions of production.

As Laila's identity changed, a new character also emerged from the experience of pain and mourning. This new persona comforts and is comforted by the group that she once rejected. At the same time, she draws from within the strength necessary to continue being what she is and to accept herself as she is, merging with a collectivity. Freeing herself from prejudice, the woman who once refused to be near people in wheelchairs ceased to exist. A new

Laila came into existence, the one who cries for other disabled people, cries with them, and tries to fight for their rights in the dialectics of life-death-life⁷.

Political life

In this context, the relationship between subject and society is reminiscent of the association between identity-building and political project. The existence of a political identity, in combination with an autonomous life project, leads the subject towards emancipation²³. The prejudiced Laila became the candidate-for-council Laila in an attempt to improve the lives of people with disabilities. In other words, she took part in the search of a future for others, in a collective political project to transform disabled persons' conditions of existence. Thus, the constitution of political identity is based on democratically built collective projects. In this sense, *identity is metamorphosis*, movement in concrete development and constant transformation, in search of *emancipation*¹⁸.

However, the systemic logic according to which the world is organized often makes it dehumanizing, especially when there is no communicative action on the part of the oppressed. As such, inequality and injustice tend to gain strength and prevail. In this sense, one's need for developing into a being-in-the-world may allow the limits imposed by a historical period's and society's objective conditions to be overcome. This adds to the importance of metamorphosis¹⁸.

Romance

Many aspects of the sexuality of people affected by disabling pathologies are forged by stereotypes, situations of rejection and discredit regarding one's affective future. However, many people manage to express their power of overcoming by transgressing social models that limit the sexual life of people with disabilities²⁴.

These transgressions, although possible, require significant effort. By being identified as "disabled", people are conferred with an attribute of lacking or having lost some intrinsic capacity that is regarded as biologically inherited. In this case, "disability" becomes a social phenomenon that leaves a stigmatic mark, both for others and for the disabled person. All the stances that Laila assumed regarding her existence – wanting to have meaningful relations, to date, to get married, to have a partner to grow old with, to be cared for – are associated and develop into the idea of "disability," which centralizes the representations of the multiple personas socially attributed to Laila.

In this sense, the construction of identity creates an ambiguous situation, establishing a network of representations that surrounds all relationships, with new characters emerging during each metamorphosis. Although they seek to break with the norms and change the symbolic and material structure of society to give rise to acceptance and a feeling of being welcome, people with disabilities also end up maintaining and reproducing stigmas, which can lead to non-emancipatory metamorphoses or block their effort towards emancipation¹⁸.

The beauty of being oneself and the communicative dimension

The manipulation of stigma²⁵ is a part of public life and depends on the contacts established between strangers and acquaintances. Thus, the task of developing methods to try to minimize society's restrictive treatment is left to the stigmatized person, who must find a way for disability to cease being a crucial, overwhelming factor in one's relationships with others.

Laila has a high regard for communication. The dialogue she establishes with her interlocutors aims to find recognition in the other, so that she can participate in the moral conventions that govern society. Her political discourse seeks to consolidate rights provided for by law, but which are yet to be fully established or even completely recognized socially²⁶.

However, valid only in certain situations, her dialogues sometimes echo in an empty chamber. If the identity-formation process is based on the reciprocal recognition between two subjects, one can only see oneself as a social subject by being recognized by others. Without recognition, there can be no formation of a social subject²⁷.

Laila's life is marked by facts that do not occur in emancipatory environments. Her constant struggle to self-produce and assert herself as a human being led her to assume different personas, all aiming towards full emancipation, in all contexts of life – be it the health/disease aspect, the process of accepting herself, her denial and acceptance of others, her search

for a partner, her fight for the rights of people in the same situation, her political candidacy, her knowledge-building effort – which included motivating her friends to enter higher education –, the “Sentindo na pele” project, or her free Spanish courses.

Her struggle, thus, is to be recognized as a human being and to obtain her rights in an exclusionary and individualistic society. For those goals, she lives, dies and lives again, changing whenever necessary in the constant search for an opportunity to be who she is. By accepting her own limitations and those of other people, Laila emancipates herself as a human being, and gives meaning to her existence. But she is still unable to count on social recognition. Her struggle is slow, silent, lonely, as many of her peers have already given up, left or died. Yet she persists and, with strong self-determination, fights to maintain her identity and lives in the hope of gaining her freedom to be, to choose, to belong, and to emancipate.

Final considerations

This study aimed to understand how the environment builds the identity of a physically disabled person – a wheelchair user – producing emancipatory metamorphoses. It is concluded that the context in which our emblematic subject is inserted is not emancipatory, as it maintains certain stigma-reproducing structures whose net effect is to hinder or even make social recognition impossible, disavowing one's satisfaction of the basic psychological need for belonging.

In her struggle, our subject seeks to free herself from socially-established segregation and marginalization. In this sense, the identity-metamorphosis syntagm is subjected to a dialectical process, in which emancipation may or may not be achieved. This study's future implications emerge from its exposition of the need to recognize the political identity of people with physical disabilities, so that they may emancipate themselves on the basis of equal rights and a social perspective aimed at humanization, belonging and social recognition for all.

For their financial support, we would like to thank the Coordination for the Improvement of Higher Education Personnel (Capes) and the Productivity Scholarship Program of the Instituto Cesumar de Ciência, Tecnologia e Inovação (Iceti).

References

1. Organización Mundial de la Salud. Informe mundial sobre la discapacidad: resumen [Internet]. Ginebra: Organización Mundial de la Salud; 2011 [acceso 10 jan 2018]. Disponible: <https://bit.ly/36l4O4b>

2. World Health Organization. Wheelchair Service Training Package: basic level [Internet]. 2012 [acesso 11 jan 2018]. Disponível: <https://bit.ly/3bquK7g>
3. Brasil. Ministério da Saúde. Política nacional de promoção da saúde [Internet]. 3ª ed. Brasília: Ministério da Saúde; 2010 [acesso 10 jan 2018]. Disponível: <https://bit.ly/307JFTv>
4. Brasil. Lei nº 13.146, de 6 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). Diário Oficial da União [Internet]. Brasília, p. 2, 7 jul 2015 [acesso 10 jan 2018]. Seção 1. Disponível: <https://bit.ly/2NdDa7C>
5. Deci EL, Ryan RM. The “what” and “why” of goal pursuits: human needs and the self-determination of behavior. *Psychol Inq* [Internet]. 2000 [acesso 15 jan 2018];11(4):227-68. DOI: 10.1207/S15327965PLI1104_01
6. Baumeister RF, Leary MR. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychol Bull* [Internet]. 1995 [acesso 15 jan 2018];117(3):497-529. DOI: 10.1037/0033-2909.117.3.497
7. Ciampa AC. A estória do Severino e a história da Severina: um ensaio de psicologia social. São Paulo: Brasiliense; 2001.
8. Meihy JCSB, Holanda F. História oral: como fazer, como pensar. São Paulo: Contexto; 2007.
9. Alberti V. Manual de história oral. Rio de Janeiro: Editora FGV; 2005.
10. Griebeler D. Emblematic subjects in the light of syntagma identity-metamorphosis-emancipation: academic productions of Nepim [dissertação] [Internet]. São Paulo: Pontifícia Universidade Católica de São Paulo; 2015 [acesso 15 jan 2018]. Disponível: <https://bit.ly/2QITRKO>
11. Brasil. Ministério da Saúde. Plano de Erradicação da Poliomielite: estratégia no Brasil [Internet]. Brasília: Ministério da Saúde; 2015 [acesso 15 mar 2018]. Disponível: <https://bit.ly/2SgWOSR>
12. Organização Pan-Americana da Saúde. Gestão de redes na Opas/OMS Brasil: conceitos, práticas e lições aprendidas [Internet]. Brasília: Opas/OMS; 2008 [acesso 10 jan 2018]. Disponível: <https://bit.ly/2NbF9cj>
13. Global Polio Eradication Initiative. Semi-annual status report: July to December 2017 [Internet]. Genebra: World Health Organization; 2018 [acesso 15 jan 2018]. Disponível: <https://bit.ly/2FbNG91>
14. Brunhara F, Petean EBL. Mães e filhos especiais: reações, sentimentos e explicações à deficiência da criança. *Paidéia* [Internet]. 1999 [acesso 11 mar 2018];9(16):31-40. DOI: 10.1590/S0103-863X1999000100004
15. Alves R. Conversas com quem gosta de ensinar [Internet]. São Paulo: Cortez; 1980 [acesso 10 mar 2018]. Disponível: <https://bit.ly/2Td8VBA>
16. Nasio J-D. Como agir com um adolescente difícil? Rio de Janeiro: Zahar; 2011.
17. Ciampa AC. Políticas de identidade e identidades políticas. In: Dunker CIL, Passos MC, organizadores. Uma psicologia que se interroga: ensaios. São Paulo: Edicon; 2002. p. 133-44.
18. Ciampa AC. Identidade. In: Codo W, Lane STM, organizadores. Psicologia social: o homem em movimento. São Paulo: Brasiliense; 1984. p. 58-75.
19. Almeida JAM. Identidade e emancipação: uma contribuição à teoria de Ciampa. *Psicol Soc* [Internet]. 2017 [acesso 20 mar 2018];29:e170998. DOI: 10.1590/1807-0310/2017v29i170998
20. Habermas J. A inclusão do outro: estudos de teoria política. São Paulo: Loyola; 2004.
21. Engels F. O papel do trabalho na transformação do macaco em homem [Internet]. São Paulo: Ridendo Castigat Mores; 1999 [acesso 5 fev 2018]. Disponível: <https://bit.ly/2FEu7s0>
22. Ciampa AC. Op. cit. 2001. p. 182.
23. Dantas SS. Identidade política e projetos de vida: uma contribuição à teoria de Ciampa. *Psicol Soc* [Internet]. 2017 [acesso 10 mar 2018];29:e172030. DOI: 10.1590/1807-0310/2017v29i172030
24. Barreto E. O corpo rebelado: autonomia, cuidado e deficiência física. Curitiba: Appris; 2016.
25. Goffman E. Estigma: notas sobre a manipulação da identidade deteriorada [Internet]. [São Paulo: Site Sabotagem]; 2004 [acesso 2 fev 2018]. Disponível: <https://bit.ly/2FJfdk9>
26. Habermas J. Teoría de la acción comunicativa [Internet]. 2ª ed. Madri: Taurus; 2001 [acesso 2 fev 2018]. v. 1. Disponível: <https://bit.ly/37Mq2y6>
27. Honneth A. Luta por reconhecimento: a gramática moral dos conflitos sociais [Internet]. São Paulo: Editora 34; 2003 [acesso 20 abr 2018]. Disponível: <https://bit.ly/2R833GO>

Participation of the authors

Valdilene Wagner conceived the scientific and logical basis for this project and wrote the manuscript. Lucas França Garcia and Tiago Franklin Rodrigues Lucena were responsible for reviewing the literature and the text. Leonardo Pestillo de Oliveira supervised the preparation of the manuscript and analyzed the results. All authors reviewed and approved the final version of the article.

Correspondence

Valdilene Wagner – Av. Guedner, 1.610, Jardim Aclimação CEP 87050-390. Maringá/PR, Brasil.

Valdilene Wagner – Master – valdilenewagner1@gmail.com

 0000-0003-2558-7832

Lucas França Garcia – PhD – lucasfgarcia@gmail.com

 0000-0002-5815-6150

Tiago Franklin Rodrigues Lucena – PhD – tiagofranklin@gmail.com

 0000-0002-0154-7417

Leonardo Pestillo de Oliveira – PhD – leopestillo@gmail.com

 0000-0001-5278-0676

Received: 12.11.2018

Revised: 5.28.2019

Approved: 5.29.2019