

O processo de metamorfose na identidade da pessoa com amputação

The metamorphosis process in the identity of an amputee

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RESUMO

O presente artigo refere-se a uma pesquisa cujo objetivo foi compreender o processo de metamorfose da identidade da pessoa com amputação. Utilizou-se a metodologia qualitativa do estudo de caso, mediante a análise da narrativa da história de vida do sujeito considerado emblemático, que foi selecionado na Divisão de Medicina de Reabilitação do Hospital das Clínicas da FMUSP. Verificou-se que, quando o sujeito consegue atribuir um sentido emancipatório ao conflito gerado pela sua amputação, ele pode rever seus valores preconceituosos e estigmatizantes acerca do significado social de ser uma pessoa com deficiência e com isso re-significar tais valores, o que propicia uma postura mais reflexiva e autodeterminada, bem como a reconstrução de seu projeto de vida com um novo sentido emancipatório.

PALAVRAS-CHAVE

Amputação, reabilitação, crise de identidade.

ABSTRACT

The present study aimed at understanding the process of metamorphosis in the identity of an amputee. A qualitative methodological approach was used for the case study, which includes the analysis of the narrative of an emblematic patient's life story, selected from the Division of Rehabilitational Medicine of HC-FMUSP. It was observed that when the individual succeeds in attributing an emancipatory sense to the conflict generated by the amputation, he/she can reevaluate his/her prejudiced and stigmatizing values about the social meaning of a person with a disability and, consequently incorporate new meanings to his/her values. That allows a more reflexive and self-determined posture, as well as the building of a new life project, with a new emancipatory sense.

KEYWORDS

Amputation, rehabilitation, identity crisis.

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Introduction

The aim of this study was to understand the process of metamorphosis of identity in amputated individuals able to attribute an emancipatory meaning to their amputation, i.e., a meaning that will free them from prejudice in order to lead more autonomous and creative lives^{1,2}. The method used in this study was the qualitative method of case study, during the analysis of the life story narrative of a subject considered to be representative, i.e., an individual who can better and more precisely express the collective consciousness than the great majority of the group³. The study population consisted of 5 individuals submitted to amputation, followed at the Division of Rehabilitational Medicine (DRM) of Hospital das Clínicas of the University of São Paulo School of Medicine (HC-FMUSP). Of the five patients, one individual considered to be the most representative for the case study was selected due to the fact that her struggle for emancipation was the most evident among the 5 cases.

The concept of identity adopted in this study, established by Ciampa², has been developed based on the presupposed concepts that are the foundation of the theoretical reference of critical Social Psychology, which, according to Lane⁴ studies the essential relationship between the individual and society, the latter understood in its historical context. It is a theoretical approach that deals with the knowledge of how each one of us – who is born as *only a natural being* is able to undergo metamorphosis into a *historical being* as well, when submitted to the determinations of the constant social transformations – becomes a human individual who, at the same time that acts as a *social actor*, becomes the *author* of actions that can determine transformations in society, which, upon becoming real, fulfill the historical process as a synthesis of nature and culture.

It is hence that identity, considered a process of constant metamorphosis, can be understood in the light of Social Psychology, as it presents the view of the human being as an active individual undergoing a constant process of transformation. Such transformation takes place within the individual and the society, reciprocally, through a dialectic process, a non-linear process in which the phenomena are considered and analyzed in their reciprocal and continuous movements of interaction.

Theoretical Reference

According to Ciampa², identity is understood as a process of permanent metamorphosis, of which the temporal dimension involves different moments. Therefore, the present is the moment at which, for instance, someone recognizes themselves as an adult that can speak of the child they were in the past – their life story – and also of the elderly they would like to become in the future – their life project – as a means of speaking about themselves.

If this individual is a person who, at some point in life suffered an amputation, the generalized presupposition, including that made by the amputee him or herself, is that his or her metamorphosis will certainly be significantly affected – which is reasonable to admit – altering the meaning of either his or her life story or life project.

What is not reasonable to admit is that this new meaning will be necessarily negative, stereotyped and stigmatizing.

Presuppositions about identities always affect everyone. Even before the birth of a child, it is possible that the future parents already have expectations that will significantly interfere with the development and formation of the unborn child. That is to say, we are born with a presupposed identity, even if it the idea that “my child will be whatever he or she desires to be, not what I expect him or her to be”. However, it is important to remember that there are other presuppositions in addition to the expectations of the significant others (as in the case of the parents), which constitute a complex net of intersubjective relationships that organizes society as a whole, involving social class, work, gender, religion, ethnicity, and age range relationships, among others.

The higher the compliance with social conventions, the more the presupposed identities are replaced i.e., are reproduced in order to consolidate a tradition that sees it as natural what is social, and consequently, historical. With the advances in Medicine, in particular, and also of science and technical aspects, in general, an amputee can simply continue to live with good quality of life. However, if the presupposed identity is that of a “failure”, an incapable or unhappy person due to the amputation, such presupposition can become a “self-fulfilling prophecy”, despite the successful care regarding surgery, prosthesis, rehabilitation, etc, which has been received.

Some objective conditions are necessary, evidently, but they are not necessarily enough, as there are also subjective conditions that can interfere. These depend on the social meaning and the personal meaning that a certain identity acquires. If the stereotype and stigma of the amputee is the intersubjectively shared meaning in society, it becomes very difficult for a person to give a different meaning to his or her life, to have a life project that will allow him or her to overcome eventual difficulties.

It is as if, from a certain point in time, the metamorphosis ceased to occur and the individual were stagnated in the “redundancy” of an impaired life, prisoner of the character that is attributed to him or her – and with which he or she identifies him or herself – of a failure, an incapable and unhappy amputee.

Therefore, even when the identity is perceived as being static, seemingly not undergoing any modification, it is being transformed as I, through my actions, “replace” what society “establishes” as right, i.e., that which social standards and the dominant ideology institute as being the most adequate. Such process can give the impression that the individual’s identity remains the same, without any transformations, but it is the replacement work that supports the redundancy². This replacement occurs when there is a reupdate of the presupposed identity, through social rituals; however, when there is such replacement, the historicity feature of identity is removed. This is what Ciampa² calls “myth” identity, in which the social aspect alone is reproduced without questioning and/or responsibility regarding the individual him or herself, in relation to his or her identity. The idea of “redundancy” corresponds to this apparent non-transformation of identity. Ciampa⁵ says that the metamorphosis, which in this case takes place by replacement, can be considered “negative”, as what is being prevented is actually

the emancipation.

The development of the identity results from the interaction of the characters incarnated by the individual. Many characters appear during people's lifetimes, and it is the individual's transformation originated from this movement of death and life, in which a character is abandoned and another appears, what allows conquering the presupposed identity and the concretization of identity as metamorphosis in search of emancipation².

Therefore, whereas it is a constant process of people's identity, the metamorphosis can acquire different meanings. When it happens as a simple substitution, without questioning and/or responsibility by the individual himself, i.e., without autonomy, when the individual substitutes the presupposed identity, he becomes a prisoner of a character that was attributed to him in a heteronomous way, remaining within a "sameness" which, if it is not exactly disagreeable, causes the person to become acritically "stagnated", preventing the individual from undergoing new experiences and relationships that will warrant a better quality of life. However, the degradation can occur when a stigma attributed by others and incorporated by the individual is efficient in deteriorating his identity with prejudiced and discriminatory actions that cause significant damage. And, finally, the metamorphosis can occur as an accomplishment, when the individual disposes of stigmatizing and prejudiced values imposed by society and/or acquired by the individual, allowing more creative and freer attitudes to achieve one's goals and desires, which is the expression of "identicalness". The expression of identicalness can also be understood as authenticity, which involves self-reflection and self-determination.

According to Ciampa², "to-be-for-oneself" is to seek self-determination, to look for the unity of subjectivity and objectivity, which makes action a finalized activity, associating desire and finality, through the transforming practice for oneself and the world."

In this regard, "to-be-for-oneself" is to leave the sameness; it is the expression of the autonomy towards the identicalness and the emancipation. This self-determination allows us to leave the substitution movement and seek the other "other" whom we also are, i.e., the "other" we want to be by overcoming the presupposed identity.

Therefore, for the identity to be self-determined as "to-be-for-oneself" and not "to-be-for-the-other", it is also necessary that this new identity of the other "other", which we want to have social recognition, in such a way that the idea of being the author of one's own life – and not only an actor that simply substitutes the coercively imposed standards – must be understood as a possibility that always occurs, at the last instance, as a collective co-authorship^{6,7}.

Thus, we can only assess whether or not there was emancipation *a posteriori*, for there is no guarantee that a new identity *essence* (albeit necessary) alone will provide emancipatory conditions to the individual. It is through the process by which this new identity *essence* of the Ego is recognized by the Alter that this personal sense stabilizes as a socially shared meaning, allowing the development of a new intersubjective net, in which the relations between the Ego and the Alter are transformed by the mutual recognition of both as autonomous individuals.

Prado* in 2001 refers to that question when reporting that: "...there is no emancipatory character in collective actions that can be pre-determined before the process that is installed in the constitution of the collective identity"¹⁸. This occurs because as the meaning of being an amputee, in collective terms, reflects stereotypes, prejudiced concepts, stigmatizing values, etc. (thus constituting a presupposed "negative" identity), it is likely that in personal terms, the sense that the individual attributes to the experience of amputation is the same, as substitution (by the Ego) of the presupposition (of the Alter) of this "negative" identity. However, this probability is not inevitable; new senses and new meanings are always possible.

If the Ego can attribute an emancipatory sense to its experience, and this sense starts to be shared with the Alter, becoming socially tangible, then there is an increase of the likelihood of new forms of reaction in the face of amputation. A new life project can arise, which will not necessarily reproduce the social stigmas of being an amputee, a life project that can be more constructive in the quality of life of the amputee.

Sofia's life story

The case study described here is about a woman, whose fictitious name is Sofia, aged 43 years, widowed in her first marriage and divorced from her second husband, with six children; she completed Grade School, owns a small business and has suffered amputations in both legs: transtibial (below the knee) in the left leg and transfemoral amputation (above the knee) in the right leg, due to a train accident in November 2001.

Sofia reports that she was always poor when she was a child, and had many limitations due to her being shy. She reports that her shyness was a problem not only in her interpersonal relationships, but also at school, as she was always ashamed of asking questions to the teachers, of showing she did not know and asking for someone else's help. This characterization of an early, strong and constant shyness allows us to affirm that she acted in her interpersonal relationships by playing "*the shy girl*" character.

When she was 16 years old, she left school to get married. Right after that, at 17 years, she lost her husband who died in an accident; she remained inside the house for three months afterwards, depressed and afraid of what her life would be after that: a widow with a daughter. This episode is again permeated by "*the shy girl*" character, who said she ignored her husband had been "in the wrong life", making the loss of her husband to be branded by two types of mourning: the one for the real husband and the one for the idealized husband. Eventually, with the help of work, colleagues and cousins, she recovered, and when she was 18 she met her second husband, with whom she was married for 25 years and with whom she had five more children. Her married life was marred by problems caused by her husband's drug addiction and jealous behavior, which the "*shy girl*" could not control, but always tried to "justify".

Sofia then reports difficult moments, during which her identity metamorphosis will take place, through her internal strength and relations with the other. Thus, when she talks about the accident

that caused the amputation, as well as the posterior hospitalization period, when she experienced moments of extreme distress and sadness and uncertainties, she states that the others had a significant role in her physical as well as psychological survival. It is during this period, according to Sofia, that the life examples set by other patients at the hospital helped her to recover and realize that, through the positive and admiration look of the other in relation to herself, there were other forms to look at herself, thus enabling her metamorphosis in the sense of identicalness, overcoming the "sameness" where the "shy girl" had been until then.

Hence, when she left the hospital, she faced other people's looks and the shame she felt in the presence of other people started to disappear, which also made the "shy girl" disappear, appearing in her place a transformed woman who started to call herself the "cheeky girl".

The "cheeky girl" character uses the strategy of, when talking to people, she looked into their eyes and showed them her potential, as she realized that the others' lack of knowledge about the disabled person increased prejudice and discrimination. Thus, by surprising the other with an attitude that was different from the commonly expected one, Sofia denied the stereotype that a disabled person is always incapable, a failure, unhappy, etc, and caused a qualitative change in her relationships, overcoming the presupposed "shy girl" identity, resulting in a transformation not only of herself, but also of the others.

Sofia's change of posture was made possible by the experience of the impact she had experimented in this phase of her life, in the face of other people's reaction to her amputations; in her narrative, Sofia told us that even her husband had shown his contempt for her, expressing everything that she feared the most when she left the hospital. He brought the prejudice into their home, degrading her female and personal identity, being ashamed of staying near her in public and showing her his contempt when he said that she was "a cripple (...) she was no longer a woman." Thus, Sofia recounted the difficult moment of the end of her marriage, but which, even representing at a first moment one more significant loss in her life, could at a second moment free her from the "sameness" that was her affective life. Hence, although her "cheeky" character already acted in many areas of her life with emancipatory attitudes, in her marriage her attitudes when performing the wife's role still reflected the "shy girl". When the "wife-that-was-also-the-shy-girl" died, the "transformed-woman-who-self-denominated-cheeky" started to live. Metamorphosis is death and life!

The reflexive attitude and self-determined posture allowed Sofia to gradually start discriminating the activities that she could regain, even if she would do them in a different way from the one she was accustomed to. When performing house chores, professional and social activities independently, she showed to the other her own potential causing admiration reactions, which stimulated her to keep performing new tasks and motivated her to keep on with her rehabilitation.

Thus, with the death of the "shy girl" who did not like to ask questions, request help from the other and show her lack of knowledge, the "cheeky girl" was born, who could rethink such values

and started to use the other's help and his intellectual resources in the rehabilitation process. The search for answers to her doubts and for further knowledge about a reality, which had been so distant for her up to that moment, enabled her to adequate her expectations and good evolution when training with the prosthesis.

It is noteworthy the fact that the transformation of identity must be understood as a full development of the individuals in all their dimensions; Sofia's improvement in her emotional dimension was also accompanied by improvements in the dimension of intellect, motor skills, interactive capability, etc. Sofia's happiness seemed to grow every time she was successful – indicating the recognition of her own increasing autonomy – as well as every time she faced a challenge – showing the opportunity to demonstrate this same autonomy. Her happiness depended very much from her being "cheeky", when she started to understand that she could show herself as her own-self; this desire made her find the courage to deny what denied her: the shame of not being what the others wanted (or who she believed they wanted her to be). She started to recognize herself – and to be recognized – as herself. The autonomy appears as a denial of the denial.

Within this context of self-development, Sofia decided to travel to her parents' hometown and perceived everyone's negative reaction due to her disability. Sofia, who had already learned how to deal with this kind of situation, puts the "cheeky" character onstage, making herself known and admired in this town. The people's negative reaction made her question, at a first moment, whether there were no disabled people in the town but, after a while, she realized that people in such condition did not have any visibility, due to the lack of space, accessibility, and knowledge of their rights, which made them stay at home.

Within this context, she decided to move to that town in order to fight for the rights of people with disabilities there. With this life project, one can say that the "cheeky" character undergoes a subtle transformation, as Sofia has her actions recognized by people and her knowledge about disabled people's rights starts to be acknowledged by the citizens, which brought her an invitation from the Town Hall to become a consultant.

To be recognized by her knowledge had always been very important for Sofia, who learned from childhood to value knowledge and were, while still the "shy girl", afraid to expose her lack of knowledge. She underwent a transformation when she stopped feeling ashamed and started to demonstrate the courage to show herself as a "cheeky girl", obtaining recognition within a context that was still limited, inside an intersubjective net still restricted to people close to her, family members, friends, etc.

Now, comes the opportunity to – not as the "cheeky girl" anymore, but as the 'specialist in disabled people's rights', who was invited by the Town Hall to be a "consultant" – to carry out a life project in which her intention of being a competent, successful and satisfied person was publicly recognized. The perception of the other who sees Sofia as someone useful for town citizens contributed to make her feel more secure and self-sufficient in showing and modifying herself according to her desires and aspirations. Therefore, Sofia also decided to go back to school in order to put

into practice her voluntary work in the town. The practice of such work brought her once more the confirmation of everything that she could build, as, even if the disability represented an objective limitation, Sofia perceived that the bigger and more real limitation was the sameness in which she lived.

Sofia regained her independence, her role as a mother, her work, and sought new forms of interaction with people; she fought for her rights, later reporting the reclaiming of her life regarding the affective aspect. Getting a boyfriend was also a significant aspect of her life, as her ex-husband had told her he did not believe in her role as a woman any more, deteriorating her female identity and bringing her doubts regarding the possibility of someday having another partner. Therefore, her relationship represented an important factor for the increase of her self-esteem, through the knowledge that she could still be loved and desired, even after the amputation.

Therefore, in the face of the emancipatory meaning that her identity metamorphosis acquired, Sofia presented as a person who has self-determined attitudes, no longer reproducing prejudiced and stigmatizing values regarding her amputation.

It is practically impossible for an individual to cease being a social actor, even when one is a hermit. However, the full individual development is only achieved when, in addition to being an actor, the person can also become, even if this is a partial or limited action, the author of his or her life story.

Thus, Sofia refers to how she considers herself as a person:

"I am a happy-go-lucky person, a happy, strong, hard-working person, aren't I? There are no obstacles for me. For me, everything works out, I say that everything works out because I go out there and do it".

Conclusion

The analysis of the life story presented here allows us to conclude that when the individual can attribute an emancipatory meaning to his or her experience of amputation, he or she accomplishes a new life project, overcoming the conflict generated by the amputation, through a review of the prejudiced and stigmatizing values about the social meaning of being a disabled person. Such review of values offers their reconsideration and the development of a more reflexive, self-determined and emancipatory posture in life, which can produce, through the communication interaction in exchange with the other, a social recognition that initiates the modification of social values, the improvement in quality of life, and the increase of the social inclusion of disabled people.

Therefore, Sofia's example is also meaningful within the collective setting of society, by showing that representative cases of individual identity metamorphosis can expand and guarantee the possibility that many others will develop their self-reflexive capacity, which can contribute to decrease stigmatizing discriminations that maintains everyone within the sameness that prevents emancipation.

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