

Panel 11: Claiming Agency in Health and Wellness Contexts

Moderator: Elizabeth Podnieks

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Between Paraphrasing and Becoming Another Self: Possible Plasticities in (Auto)biographical Narratives of People with Multiple Sclerosis

This presentation is part of a research in progress entitled “(Auto)biographies and subjectivities: the other of himself in multiple sclerosis”, that investigates the subjectivation processes in the life stories of people affected by multiple sclerosis, organized in the research of life stories of the Museum of the Person, SP. In this work, I aim to understand the narrative plasticities that the authors of those stories mobilize from the concept of time. Based on Koselleck (2014), I highlight the synchronic and diachronic factors of the consciousness conditioning and I perceive how plastic the narratives are in comparison to the experiences with the disease over time. About the synchronic factors, the narratives cover from the diagnosis moment to the point that they do a digression for the accommodation of the disease in life. All the experiences in this time originate from the events, both symptoms and prognosis, in synchrony with what is known about the disease and that mark the affected ones. The hypothesis here is that there are experiences common to all and that generate similar significations in the narrative consciousness. Upon the diachronic factors, the sluices of memory are extended also considering the life stories before the disease, identifications, values, religion, gender, choices. I notice that the factors that constitute the consciousness, and that appear in the narrative, present multiple fragments of the time previous to the experience with the disease, but also its effects, that continue to transform the subjectivities. A bigger narrative plasticity reveals itself against the opening of another sluice by the accommodations with the disease in life. In the experience of helplessness, between the hope for healing in the future and the fear of the loss of neurological faculties, this plasticity shows itself in the narratives as strength.

Entre parafrasear e tornar-se outro de si mesmo: plasticidades possíveis em narrativas (auto)biográficas de pessoas com Esclerose Múltipla

Este artigo é parte de uma pesquisa em andamento intitulada “(Auto) biografias e subjetividades: o outro de si mesmo na Esclerose Múltipla”, que busca analisar os processos de subjetivação nas Histórias de vidas de pessoas acometidas pela Esclerose Múltipla, organizadas na rede de Histórias de Vida do Museu da Pessoa, SP. Neste artigo busco entender as plasticidades narrativas que os autores dessas histórias mobilizam a partir do conceito de tempo. A partir de Koselleck (2014), destaco os fatores sincrônicos

e diacrônicos do condicionamento da consciência e percebo como as narrativas são plásticas diante das experiências com a doença ao longo do tempo.

Quanto aos fatores sincrônicos, as narrativas dão conta do momento do diagnóstico até o momento em que fazem uma digressão para a acomodação da doença na vida. Todas as experiências nessa eclusa temporal decorrem dos eventos, tanto os sintomas como o prognóstico, em sincronia com aquilo que se passa a saber sobre a doença e que marcam os atingidos por ela. A hipótese aqui é que há vivências que são comuns a todos e que geram significações parecidas na consciência narrativa.

Quanto aos fatores diacrônicos, as “eclusas da memória são alargadas considerando também as histórias da vida anterior a doença, as identificações, os valores, a religião, o gênero, as escolhas preferenciais. Entendo que os fatores que formam a consciência, e que se mostram na narrativa, apresentam extratos múltiplos do tempo anterior a experiência com a doença, mas também dos efeitos desta, que continuam a transformar as subjetividades. Uma plasticidade narrativa maior se mostra diante da abertura de outra eclusa a partir das acomodações com a doença na vida. Na experiência do desamparo, entre a esperança de cura em um futuro e o medo da perda de faculdades neurológicas, essa plasticidade se mostra nas narrativas como potência.

Raquel Alvarenga Sena Venera holds a Ph.D. in Education from the State University of Campinas, UNICAMP-SP, completed in 2009. I am a professor of the Graduate Program in Cultural Heritage and Society, University of the Region of Joinville, Univille, where I also lead the Research Group on Subjectivities and (auto) biographies. I also worked in the Graduate Program in Education at the same university until 2016, when I had to reschedule my activities for health issues. My current research focuses on the analysis of interdisciplinary (auto) biographies in contemporary discourses. I have publications in periodicals, chapters of books and annals in the areas of Curriculum, History Teaching Curriculum, curricular policies for youth. I am currently Minister of the subjects Memory and Identity, Ethics, Culture and Society and Cultural Patrimony and Social Networks in the Masters in Cultural Heritage and Society. Currently my work at the university marks a thematic deviation, from the research 'Multiple Memories and Cultural Heritage in Network: the (auto) biographical record in the face of the threat of loss'. This research is the materialization of the action in the territory blurred between researcher subject and researched subjects. It marks a digression in my academic productions from the diagnosis of Multiple Sclerosis in 2012 and the need to make adaptations of production rhythms. At the same time that I remain in the interdisciplinary place, I am open to the dialogues between fields of knowledge, but above all, the multiple voices that communicate Life Stories as cultural heritages. Although in thematic digression, the research unfolds in other researches, including the post-doctorate at the Université de Lille 3, in 2016-2017 and contributes in the epistemological experience accumulated in the last years with the analyzes of the discourses, the productions of subjectivities and the Mobilization of concepts of History, such as Time and Memory.