

INTERPERSONAL RELATIONSHIPS EXPERIENCED BY PERSONS WITH LOCKED-IN SYNDROME

10 October 2024, online, 9-12

Fernando Vidal, Opening words, 5 minutes

Welcome to all to the colloquium on “interpersonal relationships as experienced by persons with locked-in syndrome.”

I want in the first place to thank Yukiko Himeno, my dear colleague of Ritsumeikan University, for her initiative and energy in organizing this event. Thanks are also due to Ritsumeikan’s Support Scheme for International Joint Research Activities by Female Researchers for a grant to Prof. Himeno, and to the International Joint Research Promotion Program for a grant to Prof. Tatsuya Mima.

Today’s event takes place in the framework of a project I coordinate in Spain. This project, called *Anthropology and Phenomenology of the Locked-in Syndrome*, is a **multidisciplinary and international initiative** involving research groups, medical institutions, and associations, mainly from Spain, Japan and France. It brings together scholars from different fields: illness narratives, medical anthropology, disability studies, phenomenology, biomedical ethics and the humanities, as well as professionals in neuropsychology and neurorehabilitation and managers and members of patients' associations.

The institutional seat of the project is at the Medical Anthropology Research Center, in the Department of Anthropology, Philosophy and Social Work of the Rovira i Virgili University, in Tarragona, Spain. Dr. Lina Masana was in charge of field work and analysis in Spain; graduate students preparing dissertations in the project include Ana Santángelo and Lucía Denegri, who will speak later in the second session. In Japan, the project is coordinated by Prof. Mima and Prof. Himeno. We also collaborate with ALIS, the French LIS Association, and more recently with LiSA, the Locked-in Syndrome Association Community Forum launched on Facebook from Australia by Shannan Keen.

The main **overall goal** of our project is to study and describe the subjective lives and lived experience of locked-in persons and their relational and contextual conditions. This includes various dimensions of experience at the subjective and intersubjective levels, such as the illness trajectory since entering the locked-in state, views of self and others, the body and sexuality, emotions, the sense of continuity and discontinuity of personal identity, and opinions about the conditions and circumstances that make life valuable.

This goal is pursued by way of **two qualitative research methodologies**:

- the analysis of autobiographical narratives written and published by locked-in persons; and

- open-ended questionnaires and interviews with patients, caregivers and family members.

As a comparative study, our research seeks in particular two things:

- one is to compare the experience of the locked-in syndrome as caused by stroke with the locked-in state resulting from neurodegenerative conditions such as amyotrophic lateral sclerosis;
- another is to compare the experience of the locked-in state in Europe and Japan.

Since no similar investigation has ever been carried out, we hope that the present project will contribute to fill a major scientific lacuna, and have impact on care and public policy.

We would like the project to advance knowledge of the locked-in syndrome in academic and non-academic settings. We hope it can benefit patients in a variety of ways: by throwing light on broader legal, ethical and philosophical issues currently debated at the societal level; and by contributing to a case-based exploration of such issues as the assessment of treatment costs, the role of advanced directives, and the rights and obligations connected to chronic illness and end-of-life decisions.

We hope that today's workshop will be a small step toward those goals. Prof. Himeno and myself thank you all for joining, and wish you a very productive moment.

Thank you.