

DEMENTIA DIAGNOSIS BETWEEN CURE AND CARE

POLICIES, PRACTICES AND ETHICAL ISSUES IN THE SWISS CANTONS

ISSUE —

Early diagnosis and post-diagnostic support are key features of the first Swiss National Dementia Strategy 2014–2017, intended to enhance the patients' quality of life and contribute to cost containment. In practice however, early diagnosis confronts policy makers and health professionals with ethical dilemmas related to medical uncertainty, disclosure of the diagnosis and the patients' competence. At the cantonal level, the implementation of dementia diagnosis is characterized by a large diversity of practices, including regarding the ethical dilemmas. The aim of this project is to document this cantonal diversity and to understand how the socio-political and institutional contexts influence early diagnosis norms and practices.

RESEARCH DESIGN AND METHODOLOGY —

step 1 – 1st year Systematic mapping of the 26 institutional cantonal configurations that regulate dementia diagnosis (legal frameworks, policy networks, discourses); elaboration of a typology.

Methods: policy document analysis, organizational questionnaire, stakeholder interviews.

step 2 – 2nd year 3-4 in-depth case studies of dementia diagnosis cantonal policies representing the main policy types identified in step 1.

Methods: comprehensive documentary analysis, press analysis, interviews with key actors.

step 3 – 3rd year Comparative analysis of the way professionals see and handle diagnosis dilemmas in their cantonal policy contexts.

Methods: Focus groups with professionals, diagnosed patients and informal carers in the cantons selected in step 2.

OUTPUTS —

○ A comprehensive database of the 26 cantonal dementia policies;

○ An in-depth understanding of cantonal dementia policies and ways of handling ethical dilemmas;

○ An understanding of patients', carers' and health professionals' perception of "good care" and social justice;

○ Policy recommendations for the improvement of policy design and implementation with regards to dementia diagnosis and post diagnosis support.

QUESTIONS —

- ① How do different cantons formulate and implement early diagnosis policy?
- ② What are the key ethical dilemmas reported in each canton and how are they framed?
- ③ How are these dilemmas handled by professionals, patients and family carers in different cantons?
- ④ How do different policy models shape these ethical dilemmas?

HYPOTHESIS —

Our general hypothesis is that the salience of the ethical dilemmas related to early dementia diagnosis in cantonal contexts, as well as the answer given to them, is shaped by a) the articulation of the cure/care divide specific to each canton, and b) the degree to which the biomedical model of dementia has been successfully challenged by the social model of dementia.

STARTING DATE
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DURATION
36 months

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