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Dementia diagnosis between cure and care.

Policies, practices and ethical issues in the Swiss cantons.

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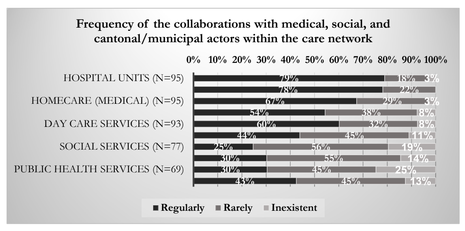
Dementia diagnosis policies and practices: diversity beyond consensus

Early diagnosis and post-diagnostic support are key features of the first *Swiss National Dementia Strategy 2014–2019*, intended to enhance the patients' autonomy and to contribute to cost containment. This federal policy is backed by shared recommendations (Bürge and al. 2018). However, dementia diagnosis and care policies differ at cantonal level; moreover, professionals of health institutions face recurrent dilemmas.

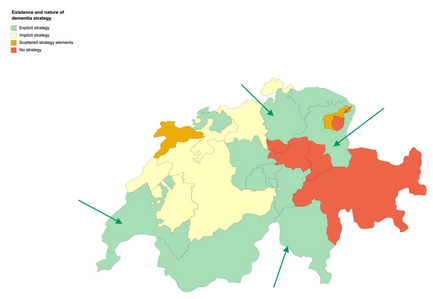
Cooperation between actors of the cure and actors of the care system *(nat. survey; n:113; RR 58%)*



Cooperation *within the medical network* is strong and satisfactory. However, cooperation with *associations* and *social services* is less common.

Diversity of cantonal dementia diagnosis policies (cantonal data base + *case studies)*

There are important differences in the levels of institutionalisation of dementia policy in the Swiss cantons: In 2019, only **half of the 26 cantons** had an explicit dementia strategy (BL, BS, GE, LU, NW/OW, SG, TG, TI, UR, VD, VS, ZH). Among them, diagnosis policies differ:



TICINO: Community-based *timely diagnosis* model.

VAUD: Delegated & centralized *early diagnosis* model.

ZURICH: Integrated care urban model of diagnosis (*early detection)*

ST.GALLEN: Decentralized un-coordinated diagnosis model

Structuring dimensions: Cantonal dementia policies; level of cantonal centralization; specificities in specialized actor's networks, logic of coordination between cure et care systems, debates about dementia diagnosis.

Most reported problems in diagnosis practice (*national survey, 6 most cited answers; % of respondants*)

Biomedical models shortcomings

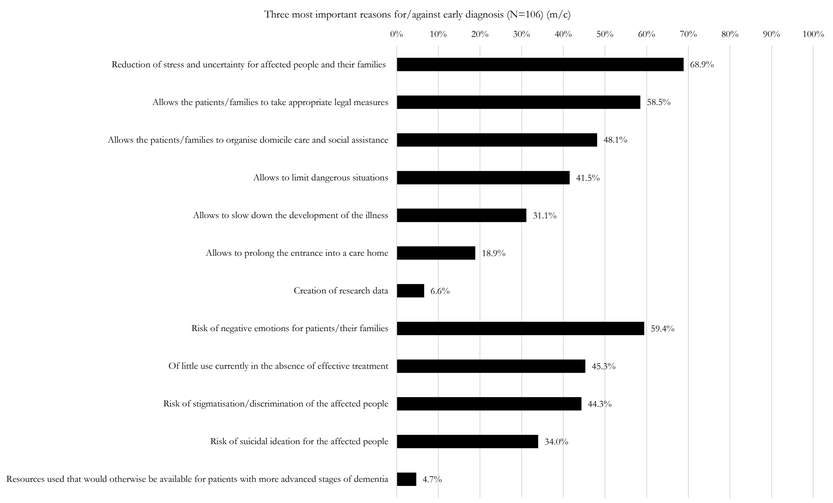
- Lack of drug-based treatment (57%)
- Formulation of diagnosis uncertainties (40%)
- Lack of non-drug based therapy (25%)

Social issues

- Driving licences management (50%)
- Lak of social support for informal carers (25%)
- Insufficiant funding by health insurance (25%)

Early diagnosis: benefits and drawbacks *(nat. survey; n:113; RR 58%)*

The promotion of early diagnosis is largely supported by the **institutions providing diagnosis** in Switzerland. However **open issues remain** regarding its implementation:



- Uncertainty of **emotional impact** of diagnosis
- **Usefulness** of early diagnosis in absence of curative treatment questioned by a significant minority
- Ambivalence with regards to **social impact of diagnosis:** promoting autonomy or stigmatisation ?

Social issues at the core of the dilemmas along the dementia diagnosis process (*case studies*: Zürich; Vaud, Ticino)

- **Professionals of the health care system face the social implications of diagnosis for both the patients and their families.**
- **Shared issues along the process refer to the people reluctance to diagnosis, driving licence management, inequality of access to post-diagnosis long term care at local or cantonal level, implication of the family carers.**
- **There is a need (and a strong potential) for increasing coordination between diagnosis health structures and social care organizations**

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