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Unformulated expectations in dementia care A mediation experiment in three Swiss regions

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Three points of the speech

- 1. What dementia case highlights
- 2. A mediation experiment (Uni Geneva)
- 3. Conclusion: the role of mediation in the field of elderly care

1. What dementia case highlights

- Dementia in the context of the swiss health care system (acupuncture needle)
- Three main issues for mediation

a. Definition of « good care »

- The importance of **care** (vs cure)
- Changing needs (vs static social services)
- The importance of family carers
- The complexity of care networks

b. The backing of transitions

- « Diagnostic »
- **Home-based care**
- Institutionalisation
- End of life

c. The democratic issue of care reforms

The « democratic vulnerability » with regard to dementia

- **Patients and family**

- Home based (60%),
- Taboo surrounding dementia,
- Exhausting care

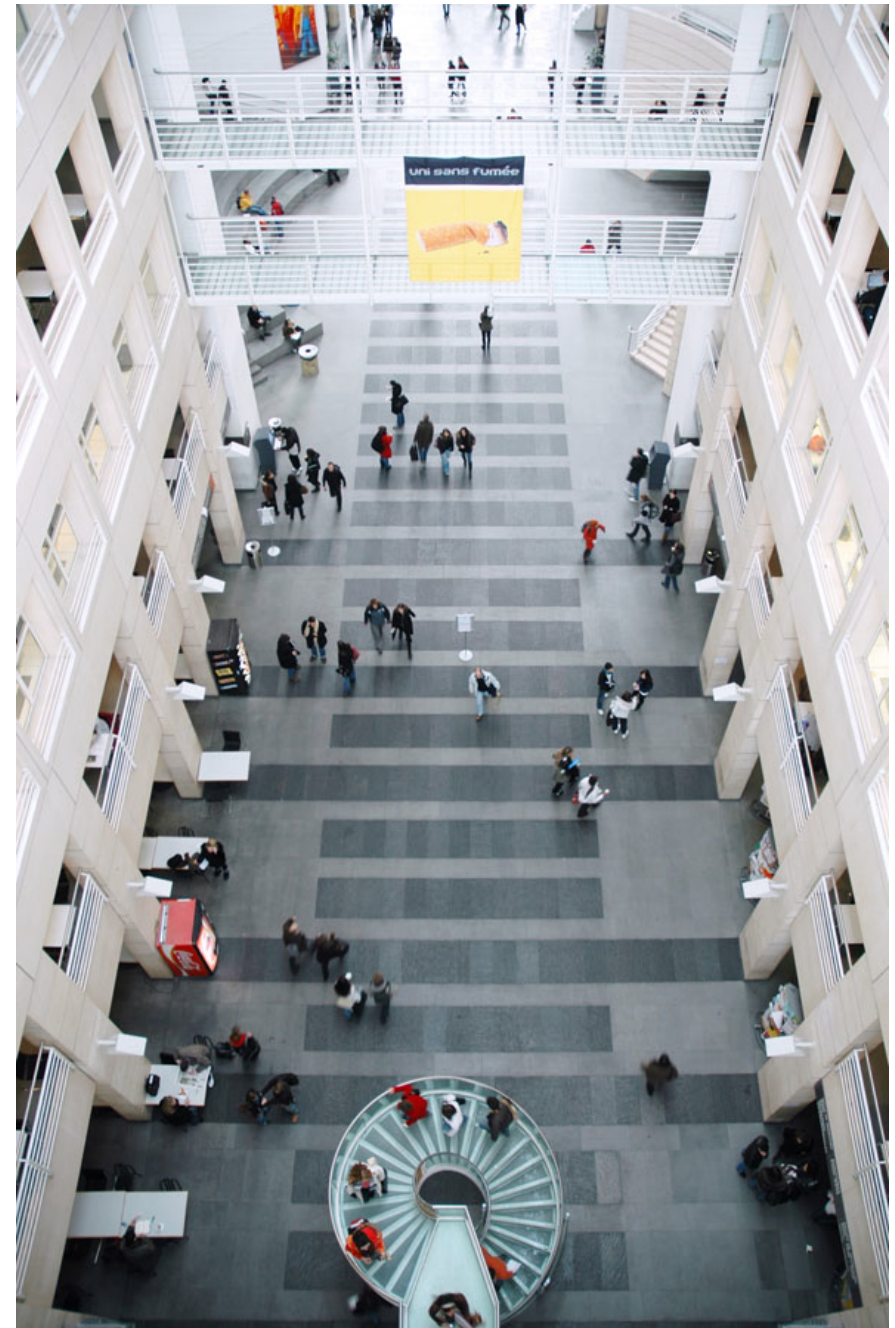
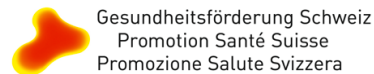
- **Care workers**

- Devaluation of care work
- Low wages
- Weak formal responsibilities
- Illegal workers

2. Dementia home-based care A mediation project



Fonds culturel Migros

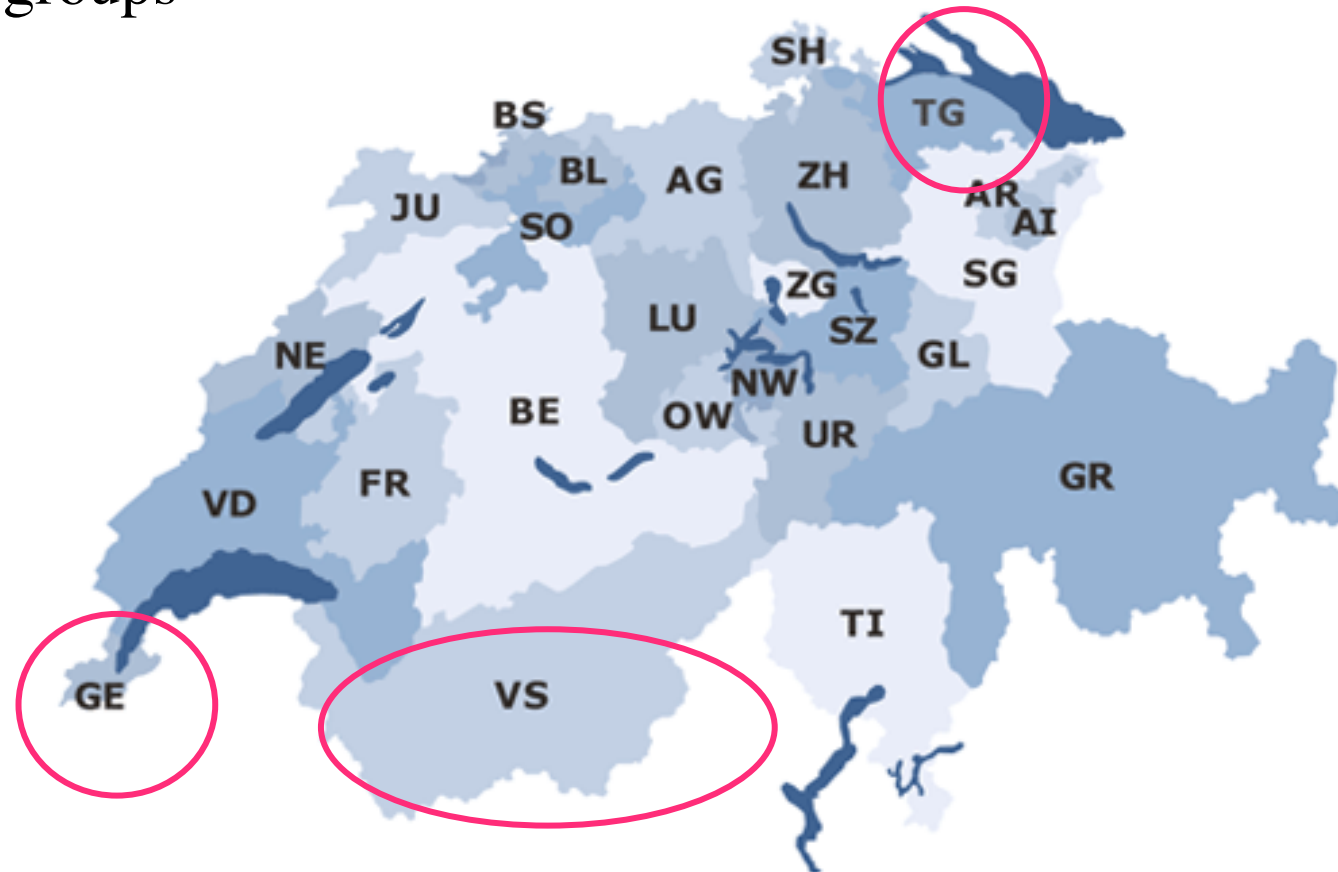


Focus on the relation family carer- external carer

- A « conflictual cooperation »
 - Cooperation for the well-being of the patient
 - Conflict: lines of tension
- Conflictual dimensions
 - Opening up privacy *via* external intervention
 - Domestic vs professional logics
 - Asymmetry of relations (patient and family carer in situation of dependancy)

Three Swiss cantons

57 participants
16 focus groups



Overcoming the gap of conflicting expectations

- 1. Focus groups with family carers (children, husbands, wives) (2)
- 2. Focus groups with with external carers (professional, volunteers, illegals) (2)
- 3. Indentification of mutual expectations and propositions
- 4. Mixt group: validation, confrontation, and discussion of propositions (1)

The gap of expectation

Difficulties formulated by family carers (exemples)	Difficulties formulated by external carers (exemples)
The rigidity of intervention practices impedes a tailored intervention	Families' demands may exceed the external carers' responsabilities
The knowledge of the family is not recognised by professionals	Families sometimes try to impose their vision of the patient
The external carers have no time for relations	Communication with the family is complicated by their fear of the disease
Family carers' needs are not taken into account	Families do not understand the limit of our intervention

The convergence of discourses of family carers and formal carers

- **The common definition of care**
 - patient as a subject
 - relational dimension, time and continuity
- **The demand for recognition** (informal and formal carers)
 - Recognition of care and care work
- **The impact of structural factors on relations**
 - Financial barriers, quantity and access to services, relief services

Suggestions

- **Improve communication (mediation)**
 - Communicative spaces for the family
 - Deliberative decisions
 - Improved access to information
 - Care referent (mediation between changing family needs and health and social system)
 - Inclusion of family carers in professional training
- **Improve structural support**
- **Concrete prevention concepts (each canton)**

3. Conclusion

In the light of dementia, what can we learn regarding

- the care relation ?
- the importance and role of mediation in the field of care?

The care relation

- An open relation:
 - can be questioned, modified
 - importance of third party in the relation between patient and family members, and between family members and external carers
- A relation determined by the context
 - Institutions, provisions of services, financial supports

The role of mediation in care

- From conflict resolution to empowerment
- Mediation as institution:
 - Support of care relations (family-patient; family-external carer)
 - Opening the relationship (sharing responsibilities)
 - Providing communicative spaces
- Mediation as an instrument of empowerment
 - For patient, family and care-workers
 - Access to public debate while respecting confidentiality

- References:

- Lucas, B. et O. Giraud (2010). *Les soins à domicile pour les malades d'Alzheimer et autres démences: tensions et prévention des tensions*. Université de Genève, Institut de recherche sociale et politique.
- Lucas, Barbara (2009). “La dépendance: nouveaux enjeux pour la médiation. L'exemple de la maladie d'Alzheimer”, dossier « Les médiations en question », *Nouvelles Pratiques Sociales*, UQAM, Montréal: 109-123.