

UNIVERSITY OF LUXEMBOURG Integrative Research Unit on Social and Individual Development (INSIDE)

## HEALTH CAPABILITY OF FAMILY CAREGIVERS

## Contribution of, and relations between its dimensions

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## Family caregivers and their health

Context 

Methodology 
Results 
Discussion

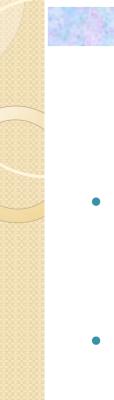
#### • A growing public health challenge

- Complex care provided day to day in addition to personal life
- About 10% of the population
- A lifestyle which entails risks for their health (2 meta-analyses):
  - Problems with physical health (Vitaliano & al., 2003)
  - Stress, depression, (Pinquart & Sörensen, 2003)

#### + Social isolation

(Spitz & Sordes, 2007)

- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A metaanalysis. *Psychological bulletin*, 129(6), 946–972.
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and aging*, 18(2), 250.
- Spitz, E., & Sordes Ader, F. (2007). Qualité de vie, entourage, soutien social. In *Qualité de vie et maladies rénales chroniques: satisfaction des soins et autres Patient-Reported Outcomes*. John Libbey Eurotext, Paris., pp. 109–123.



## The capability approach

Context → Methodology → Results → Discussion

- Developed from the 1980's by Amartya Sen (Sen, 1992)
  - Welfare economist and philosopher
  - Nobel Price of Economy in 1998
- A way to conceive quality of life
  - Alternative to economic models of development:
    - Resourcist (economic development)
    - Utilitarist (improvement of satisfaction)
- Capability
  - What a person can do or be according to the choices which really are available to them

## Capability approach: Application to health

Context 

Methodology 
Results 
Discussion

- Capability to be healthy
  - Fundamental for human dignity (Sen, 1993; Nussbaum, 2011)
  - A complex set of capabilities (Venkatapuram, 2011)
- Contribution of health economics
  - Finding indicators of capability to evaluate health interventions
  - Reconsider health & health-related quality of life to measure effectiveness
  - Questionnaires of capacity to accomplish valued domains of life

(Coast & al., 2008; Kinghorn, 2010; Al-Janabi & al., 2012)

Nussbaum, M.C., 2011. Creating capabilities. Harvard University Press.

Venkatapuram, S. (2011). Health Justice. Polity Press.

Kinghorn, P. B. (2010). Developing a Capability Approach to Measure and Value Quality of Life: An application to chronic pain. University of East Anglia.

Al-Janabi, H., Flynn, T. N., & Coast, J. (2012). Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. Quality of Life Research, 21(1), 167–176.

Sen, A. (1993). Capability and well-being. The quality of life, 1(9), 30–54.

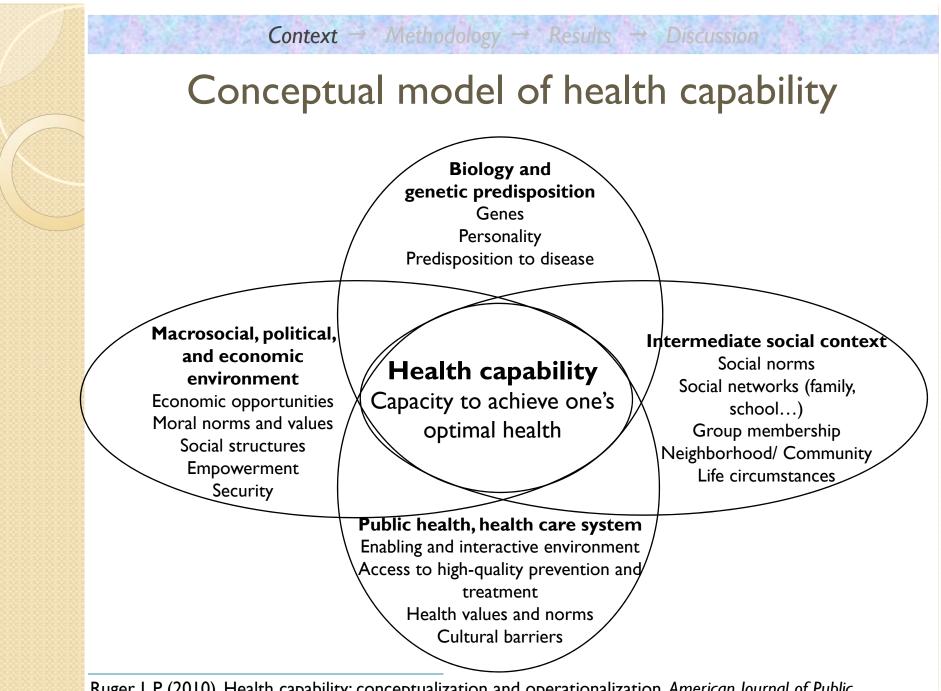
Coast, J., Flynn, T. N., Natarajan, L., Sproston, K., Lewis, J., Louviere, J. J., & Peters, T. J. (2008). Valuing the ICECAP capability index for older people. *Social science & medicine*, 67(5), 874–882.

# The Health Capability Paradigm (Ruger, 2010)

Context → Methodology → Results → Discussion

- Medical ethics and health politics
- Theory of a right to health
- Capacity to achieve one's optimal health
  - Health status (functioning)
  - The way a person takes care of his/her health (agency)
  - Choice?

Ruger, J. P. (2010a). Health and social justice. Oxford University Press, USA.



Ruger, J. P. (2010). Health capability: conceptualization and operationalization. American Journal of Public Health, 100(1), 41–49.

## HCFC-8 domains: a tool for measuring health capability of family caregivers

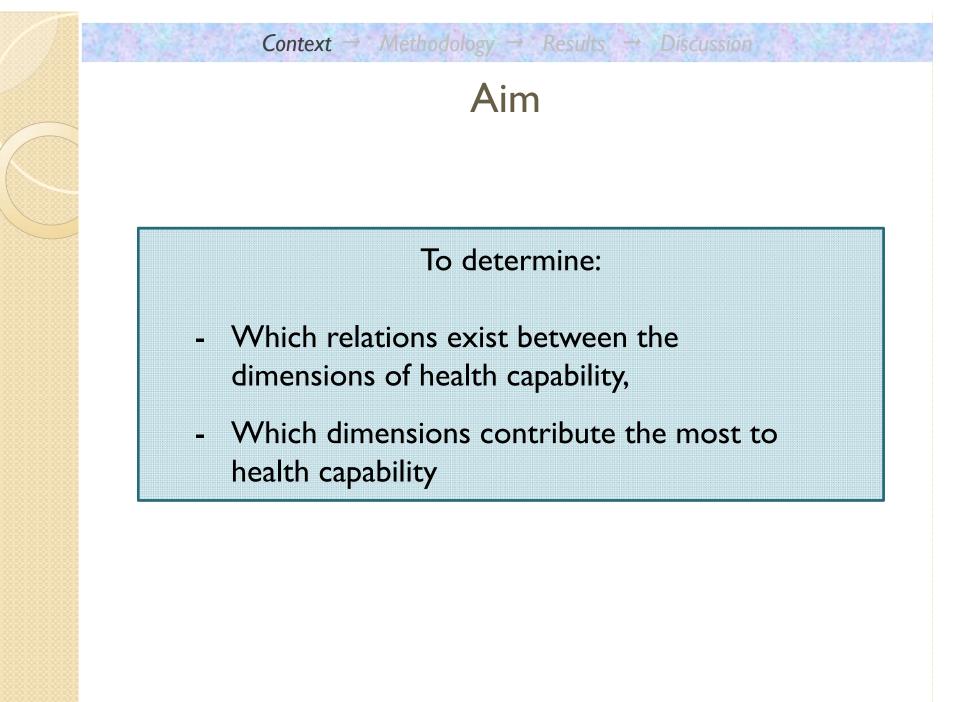
Context 

Methodology 
Results 
Discussion

- National stroke survey Luxembourg
- Health Capability of Family Caregivers questionnaire (8 domains - 20 items; Bucki, 2014)
  - Psychological health (3 items),
  - Physical health (2 items),
  - Self-efficacy (2 items),
  - Lifestyle value (3 items),
  - Family support (3 items),
  - Social capital (3 items),
  - Material condition / Security (2 items),
  - Satisfaction with health services (2 items)

#### Psychometric and content validity tested

Bucki, B. (2014). *Health capability of family caregivers: Analyses of the paradigm and means of operationalization.* University of Lorraine and university of Luxembourg, Metz, France.



## Methodology

Methodology - Results - Discussion

#### Participants

 Family caregivers who participated to the Luxembourg stroke survey (n=62)

#### Design

• Face-to-face structured interviews

Context →

#### Instrument

• HCFC-8 domains questionnaire

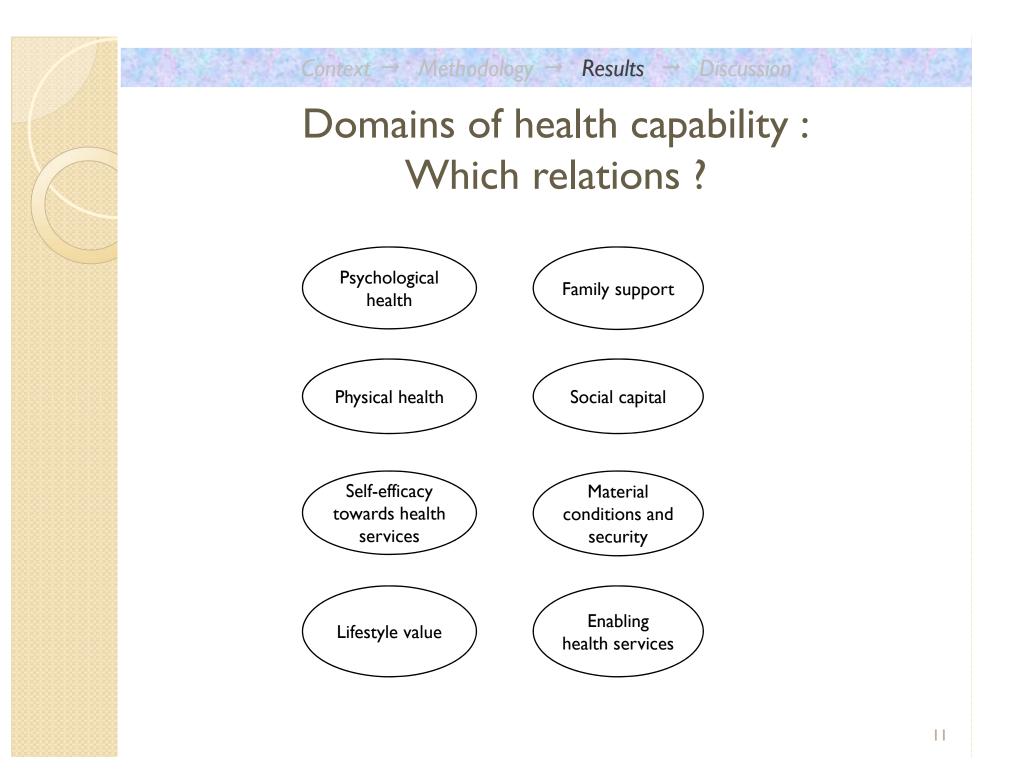
#### Statistical analyses

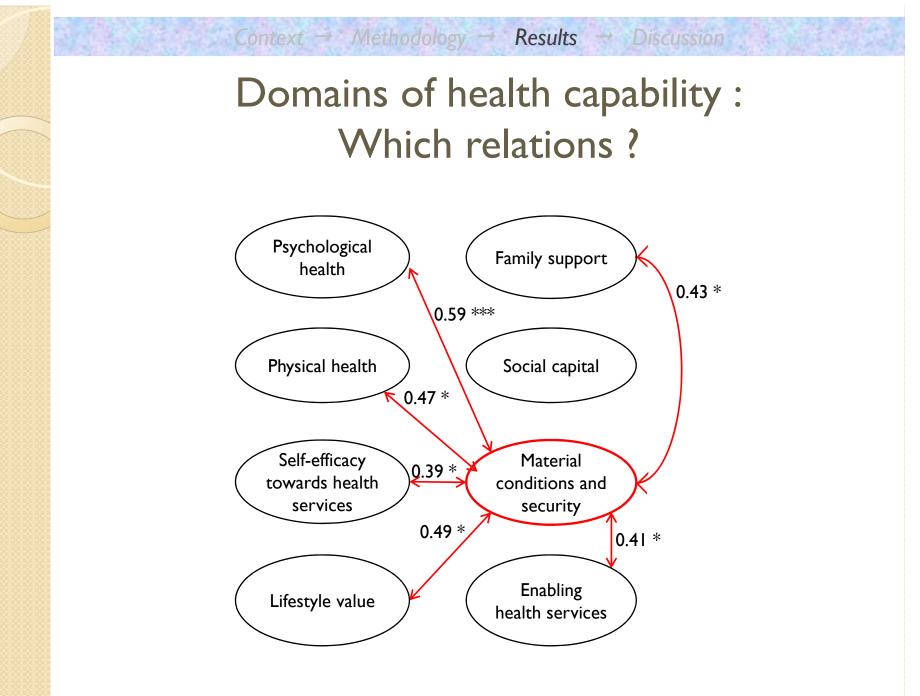
- Bayesian approach
- Structural equation modelling

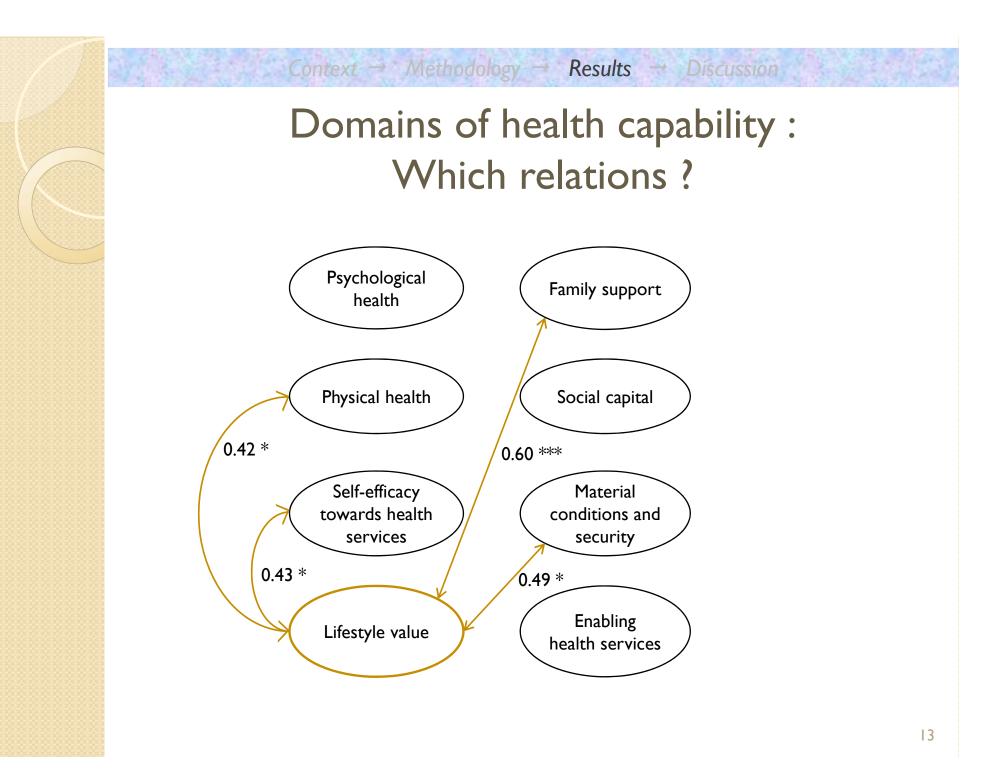
### Context → Methodology → Results → Discussion

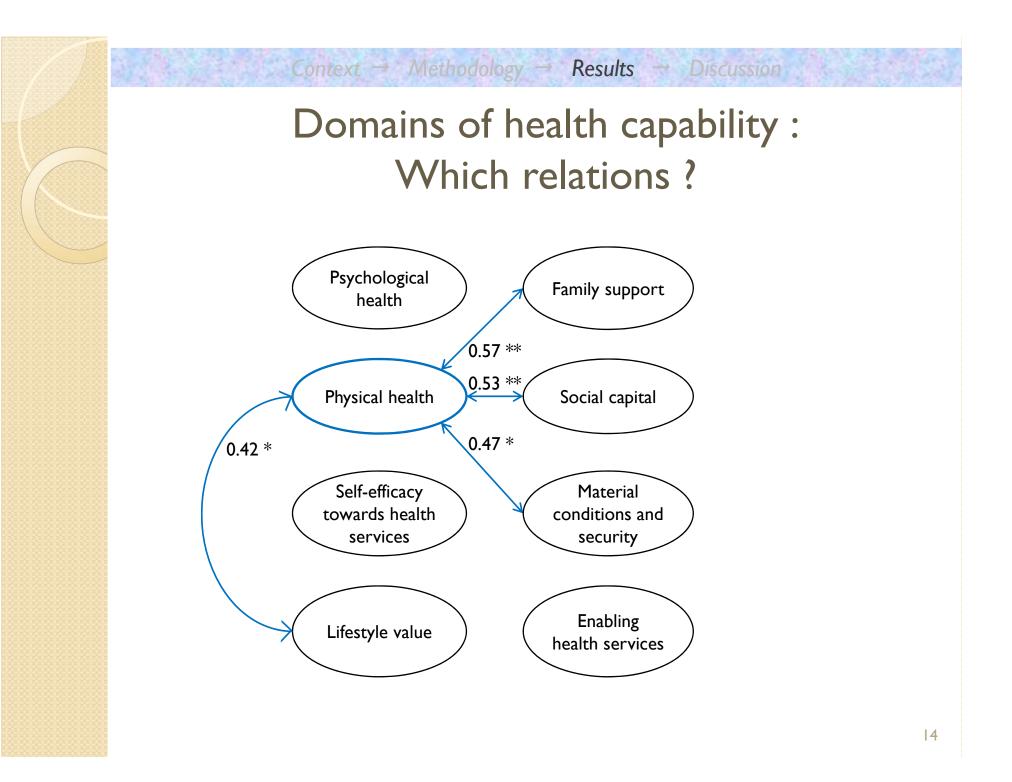
### Characteristics of the sample

- n=62
- 64.5% women
- 85% partners
- Average age : 59.3 (± 13,7)
- ≈ 50% of caregivers accompany victims who have motor and/or sensory (especially pain) impairments

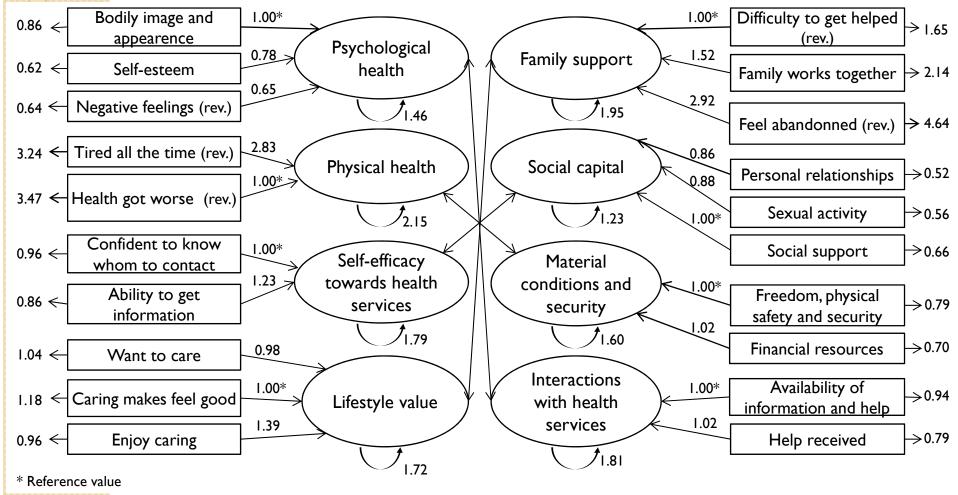


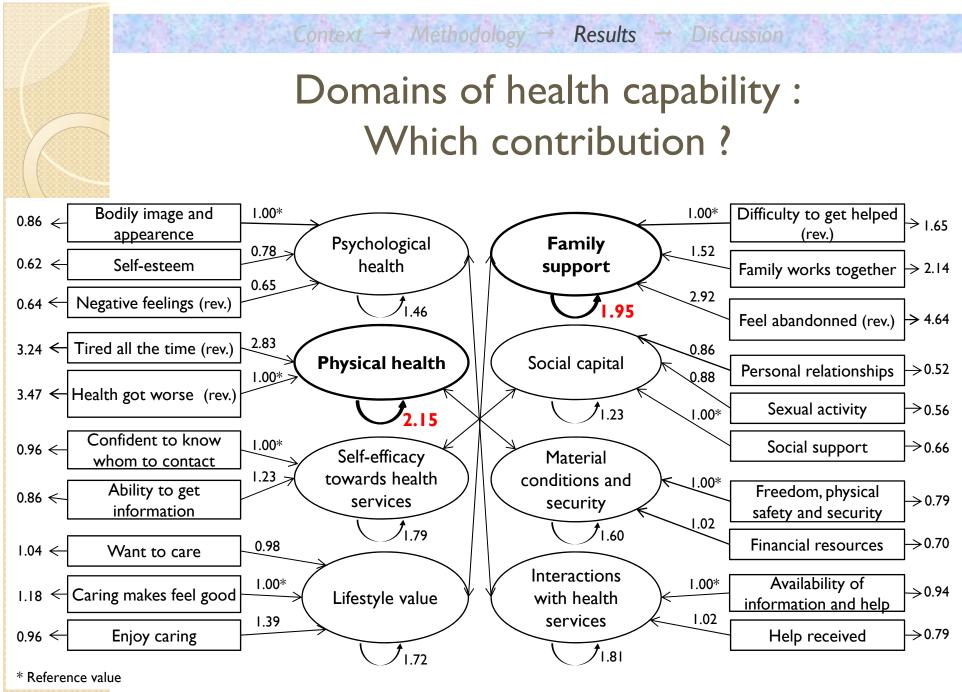


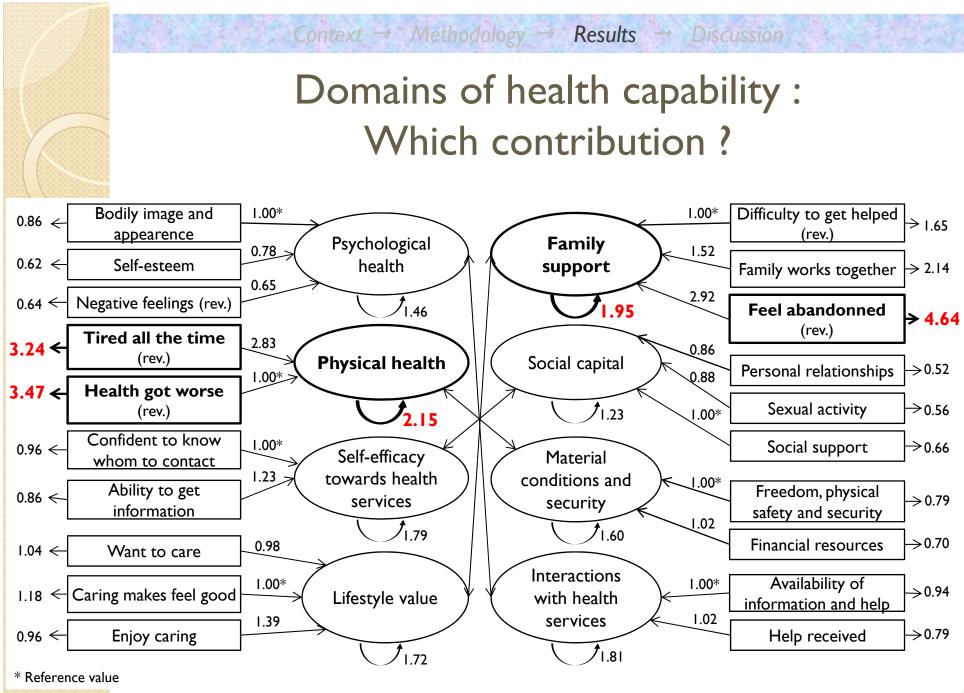




## Context → Methodology → Results → Discussion Domains of health capability : Which contribution ?







## Enhance family caregivers' health capability

Discussion

Context  $\rightarrow$  Methodology  $\rightarrow$  Results  $\rightarrow$ 

#### • Find ways to:

- relieve them physically,
- foster family networking around the ill

+ giving priority to the socially disadvantaged

#### • For example:

- Trialogues (Amering, 2010)
- Access and training to Information and Communication Technologies

Amering, M. (2010). Trialog-an exercise in communication between consumers, carers and professional mental health workers beyond role stereotypes. *International Journal of Integrated Care*, 10 Suppl, e014.

## Limits

Discussion

Context → Methodology → Results →

#### • Sample size

 $\Rightarrow$  Impossible to generalize the results

⇒ Need to validate the HCFC questionnaire with a larger sample

#### • Cross-sectional study

⇒ How has health capability evolved ?

## Perspectives

Discussion

- Finalize the HCFC questionnaire
  - Complete the domains and items
  - Administer to a new and larger sample of caregivers

Context → Methodology → Results

- Validate the final version
- Applications of the HCFC questionnaire
  - Evaluation of complex health interventions
  - Diagnosis of family caregivers' needs
- A European research project in preparation

## Thank you for your attention.

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