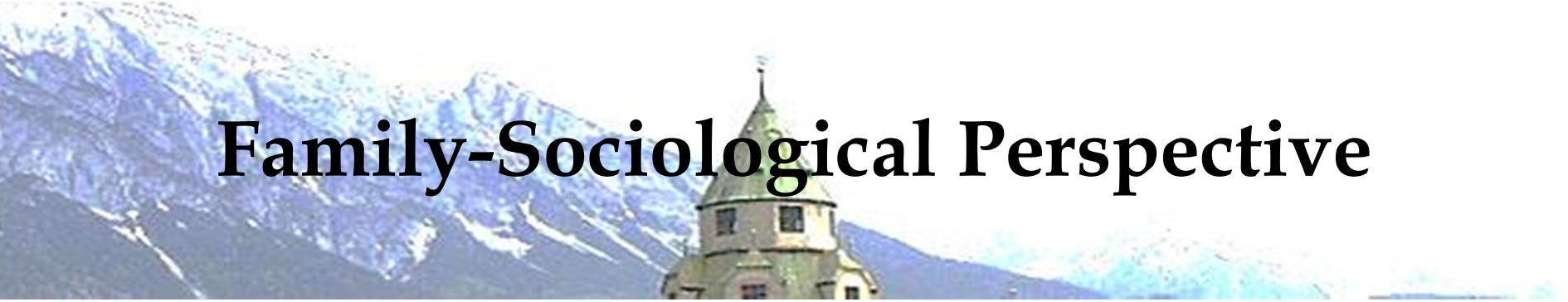# Paternalism in families – burdens of caregivers of elderly family members

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Family-Sociological Perspective

➡ Family-socialization: from the „whole house" to the nuclear family (statistical appearance). (Peukert 2008; Rosenbaum 1982; Brunner 1978)

➡ Multi-local and multi-generational families. (Bertram 2000)

➡ Socio-demographic changes: beanpole families. (Rosenthal, Burton 1990; Schattovits 2000; Hoff 2006)

➡ Sociopolitical influences: subsidiarity principle, social security, pension reform. (Rosenbaum, Timm 2008)

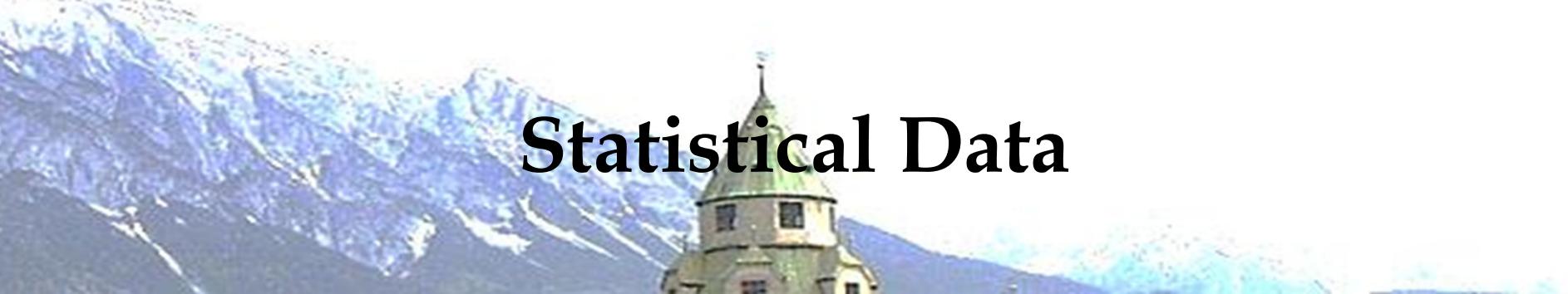➡ Autonomy of generations: resources – support. (Attias-Donfut 2000)

Psychological Perspective

Paternalism (Grill 2010; May 2001; Wicclair 1993; Cicirelli 2003)

- Paternal action: patriarchy (pater-father; archy-rule).
- Violent intervention in personal freedom and autonomy.
- For the benefit of another person.
- Medical Ethics – between two poles:
    lack of capacity to consent and self-fulfillment.
- Informal care - between two poles:
    autonomy and paternalism.
- Closely linked to dependency.

- **Conflicts within emotional bonds and loyalties.**
- **Parentification.**
- **Delegation.**

Statistical Data

Germany 2013: People in need of care divided according to types of care.

2.5 million people in need of care

Informal care: 1.76 million people (70%)

Residential care: 743,000 people (30%)

Family caregivers unassisted:
1.18 million people

Together with mobile nursing services:
576,000 people

Impact on Practice

Informal Care (Blome, Alber et al. 2008; Wingenfeld, Büscher et al. 2008; Hoff 2006; Schattovits 2000)

➡ A new definition of `need of care´ is necessary – in social and health politics.

➡ Increase in very elderly people – decrease in caring family members.

➡ Within four generations mostly two generations are in need of care.

➡ Larger distances and relationship varieties increase burdens of caregivers.

➡ Political and social conditions for family caregivers claim high personal and financial sacrifices.

Research Project

3 research groups:

➡ First step: 13 informal caregivers of non-institutionalized older family members are interviewed. All caregivers are sandwiched between own children and aging family members.

➡ Second step: 13 informal caregivers of older family members in residential care are interviewed.

➡ Third step: the data obtained in steps one and two are discussed with nine different experts.

Results – Research Group 1

Categories	Subcategories 1	Subcategories 2
Intergenerational relationship	Children in debt to their parents	Feel guilty / obligation to care / to give sth. back.
Effects on family relations	Strong conflicts with elderly family members in need of care/ careless towards own family	Parents obstruct care / difficulties to decide for their parents, to make decisions/ little support from family / married life is neglected / children are disadvantaged.
Burdens of caregivers	Permanent stress and strain / fear of the future	Burdens caused by multiple roles in life / no recovery / financial problems / can´t satisfy the expectations / long for the end.
Changes in own life	High personal sacrifices and losses	Sacrifice of personal needs / financial and social restrictions / lack of spontaneity / restrictions in working life / conflicts with social and health authorities

Results – Research Group 2

Categories	Subcategories 1	Subcategories 2
Intent for residential care	Exhaustion of the caregiver / better care for elderly (parents)	Workplace, social and personal burdens / deterioration of health / failure of alternative care-systems / third-party advices.
Emotional effects	Strong feelings of guilt / as time passed by the situation improved	Conflicts with elderly persons in residential care/ taking parents back home/mental-emotional stress of former caregivers/mental illness of former caregivers/mental degeneration and increasing morbidity helped managing the situation
Social effects	More time for personal needs / high personal restrictions	Less psychological burdens / less burdens in daily life / more freedom / more social contacts / financial losses / personal and health restrictions / conflicts and disputes with care institutions, official sponsors and authorities

Results – Research Group 3 / Experts

Categories	Subcategories 1	Subcategories 2
Conflicts of caregivers	Psychological conflicts / fear of the future	Burdens caused by feelings of guilt / decision conflicts / disputes in the family / fear of social strains / fear of financial conflicts.
Burdens of family caregivers	Family caregivers' exhaustion / psychological strain	Excessive demands on family caregivers / lack of support and advice / conflicts with caring partners and institutions / long-term stress /
Structural aspects	Lack of advice / inadequacies in structures and social, political and health environments	Need for information and educational work / excessively high requirements for official caregivers / social and health policies don´t facilitate better care and support systems

Overview of Findings

1. How do people experience burdens of caring for their elderly family members?

Long-term stress and strain – long for the end; can´t satisfy their own or expectations of others; confronted with decision-making; confronted with feelings of guilt; obligation towards older family members; financial loss; restrictions and worries; no support and advice.

2. What impact has care-giving on personal relationships?

Whole family is affected; feelings of guilt; conflicts and arguments; own needs and wishes are not compatible with those of other family members; paternalistic decision-making happens daily – these decisions are very difficult to take; as the disease progresses paternalistic decisions will come easier; more time for privacy.

Explanatory Approaches

Gerontology: (Ernst 2008; Opaschowski 2008; Peters 2004)

➥ Transition to retirement is regarded as a critical phase of life.

➥ Caring for parents/elder family members complicates own aging.

➥ Unexpected changes and duties in life.

Sociology: (Kaiser 2007, Ernst 2008)

➥ Changing family structures.

➥ Middle-aged adults in a "sandwich position".

➥ High burdens due to multiple roles in life.

➥ Conflict-potential arising from diametric expectations.

Explanatory Approaches

Care science and health care: (Hicks, Lam 1999; Schmidt 2005; Ehrhardt, Plattner 1999; Zank, Schacke et al. 2007)

➡ Dilemmas in care situations – decision-making conflicts.

➡ Complex decision-making processes.

➡ Moving into a nursing facility burdens the whole family.

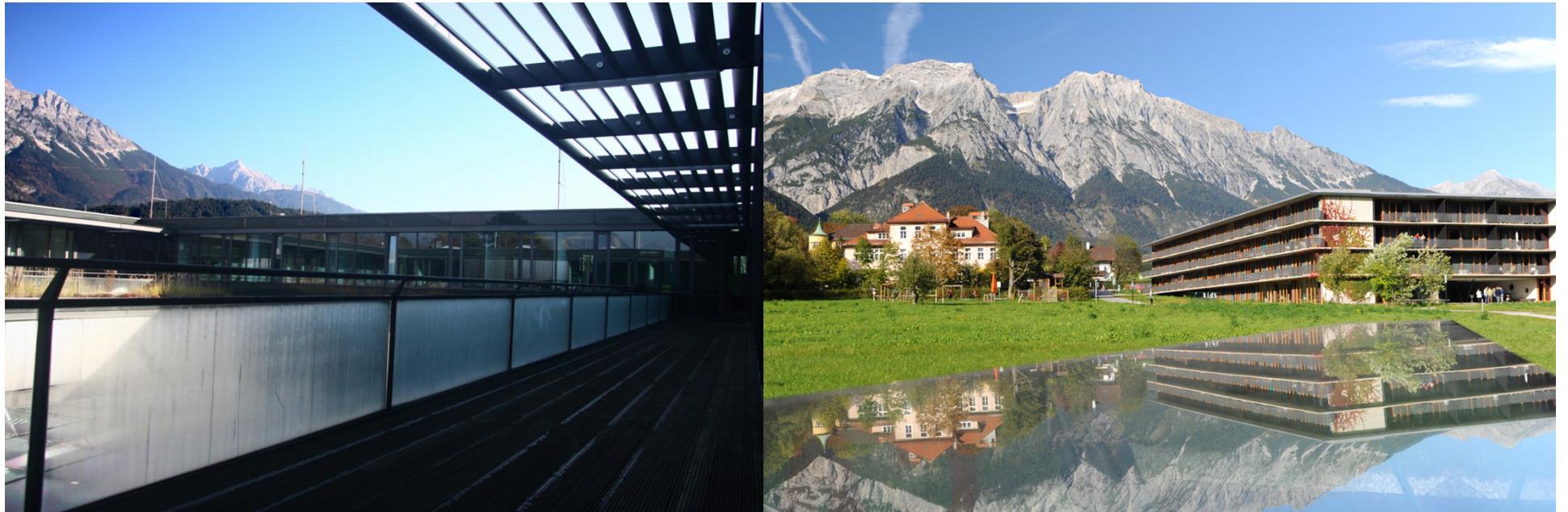➡ Lots of difficult bureaucratic processes.

Explanatory Approaches

Paternalism in daily care-giving (Cicerelli 2003; Wicclair 1993)

➡ Conflicts in daily routines.

➡ Bad conscience/ feelings of guilt / conflicts.

➡ Parentification – the elderly don´t accept decisions by younger family members.

➡ Difficult decision-making towards the end of life.

➡ Burdens of caregivers of middle-stage dementia patients are extremely high.

Outlook

➡ Family resources will continue to decline.

➡ Burdens of informal (family) caregivers will continue to increase.

➡ Burdens have multidimensional character

   >>> need for cross-disciplinary support and advice.

➡ Coaching, supervision.

➡ Care, support, information/advice should be organized in networks.

➡ Not just a health-political problem > cities, communities, welfare, employers etc. are also responsible.

   >>> Public-private partnership. (Blome, Alber et al. 2008)

➡ Political reforms are conceptualized too slowly and still have to prove their value.

Thank you for your attention!

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