

Feelings of Family Caregivers Towards the Cared-for Person With Dementia – A Micro-Analytic Approach

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Paper presented at the 20th Alzheimer Europe Conference “Facing dementia together” 30 September – 2 October 2010, Luxembourg.

Feelings of Family Caregivers

- **Caregiving can have beneficial and detrimental consequences (Beach, Schulz, Yee, & Jackson, 2000; Brown et al., 2009)**
- **Caregiving for a person with dementia can lead to psychiatric and physical morbidity (Schulz, O'Brien, Bookwala, & Fleissner, 1995)**
- **Different pathways to caregiver burden (Monin & Schulz, 2009)**
- **Suffering is highly unique and not comparable between individuals (Black & Rubinstein, 2004)**

Research Questions

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. *Qualitative Results*
5. *Discussion*

Assumption of multiple facets of caregiver burden

1. *Emotions and attitudes towards the cared-for person and towards the partnership?*
2. *Subjective theories about causes and explanations for dementia?*
3. *Basic perceived characteristics of the caregiving situation?*
4. *Changes in subjective experiences over time?*

Data Collection and Analysis

1. *Research Questions*
2. **Data Collection**
3. *Validation*
4. *Qualitative Results*
5. *Discussion*

The 72-year old woman **Mrs. W.** caring for her 88-year old husband

The 75-year old **Mr. L.** caring for his 72-year old wife

t_1 - and t_2 -interviews were not focused on the caregiving situation!

Qualitative analysis with abbreviated version of grounded theory (Willig, 2008)

Validation with Quantitative Measures

1. *Research Questions*
2. *Data Collection*
3. **Validation**
4. *Qualitative Results*
5. *Discussion*

Well-Being and Health Measures

- Perceived Burden of Life Situation
- Positive and Depressive Mood
- Self-rated Health Status
- Autonomy, Adjustment to Living Situation, Life Satisfaction
- Social Satisfaction
- Self-Esteem

Quantitative Well-Being Measures

1. *Research Questions*
2. *Data Collection*
3. **Validation**
4. *Qualitative Results*
5. *Discussion*

Compared with the total sample ($N = 62$, resp. 56, $M = 77$ years), Mrs. W. and Mr. L. report ...

- more burden of life situation
- worse health
- more depressive symptoms (Mr. L. only t_1)
- less autonomy
- less adjustment to living situation
- less life satisfaction (Mrs. W. only t_2)
- worse mood
- less social satisfaction (all p values $< .001$)

1. Emotions and attitudes and perceived consequences of caregiving

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. ***Qualitative Results***
5. *Discussion*

Specifics

Mrs. W.:

- ambivalent emotions: towards (1) having husband at home, (2) living situation, and (3) ambulant care
- grateful for good days
- consequences: less energy and endurance, more nervousness
- “fading away”

1. *Emotions and attitudes and perceived consequences of caregiving*

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. ***Qualitative Results***
5. *Discussion*

Specifics

Mr. L.:

- distance
- past: wonderful partnership
- now: “malfunction”
- no control over situation, no responsibility
- aggression and frustration
- t3: responsible for spouse’s well-being, worries
- consequences: own physical impairments more difficult to deal with

1. *Emotions and attitudes and perceived consequences of caregiving (ctd.)*

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. ***Qualitative Results***
5. *Discussion*

Similarities

Mrs. W. and Mr. L.:

- worries and sorrow
- it feels good to do something good for spouse (Mrs. W.: care, Mr. L.: nice little gestures)
- reminiscing about former better times (Mr. L. also worse times)

2. Which subjective theories exist about causes and explanations for dementia?

- 1. Research Questions*
- 2. Data Collection*
- 3. Validation*
- 4. Qualitative Results***
- 5. Discussion*

Specifics

Mrs. W.:

- due to high age of husband

Mr. L.:

- not due to her smoking
- due to spouse's laziness and immobility
- t3: due to birth of child with severe disabilities who died at age 17

3. What are the basic perceived characteristics of the caregiving situation?

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. ***Qualitative Results***
5. *Discussion*

Similarities

- high amount of time spent for caregiving
- need to get external help due to physical constraints
- structure daily routines around needs of spouse
- withdrawal from social activities

3. What are the basic perceived characteristics of the caregiving situation?

- 1. Research Questions*
- 2. Data Collection*
- 3. Validation*
- 4. Qualitative Results***
- 5. Discussion*

Specifics

Mrs. W.:

- fluctuation of symptoms
- open future time perspective

Mr. L.:

- own physical impairments make situation worse
- no consolation in future

4. What changes in subjective experiences can be observed over time?

- 1. Research Questions*
- 2. Data Collection*
- 3. Validation*
- 4. Qualitative Results***
- 5. Discussion*

Specifics

Mrs. W.:

- t1 – t2: deterioration of her and husband's functional status, more need for external help

Mr. L.:

- t2 – t3: remarkable break, new explanation for spouse's functional status, less blame for his wife

Discussion

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. *Qualitative Results*
5. ***Discussion***

- Similarities and specifics: Basic characteristics versus subjective experiences of caregiving situation
- Caregiver suffering produces different symptoms and is attributed to different causes
- Own health status makes a difference!

Discussion (ctd.)

1. *Research Questions*
2. *Data Collection*
3. *Validation*
4. *Qualitative Results*
5. ***Discussion***

- Policymaking and care management:
 - Reminiscing as coping strategy
 - More education on dementia is necessary → No responsibility!
 - Personalized interventions are necessary to reduce specific physical and psychological stressors

Thank you for your attention.

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