Incongruity of perspectives: Self-reports of persons with dementia and evaluations of their spouses and caregivers – results and conclusions from a systematic review

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Mission Statement

Aim of the DZNE Witten is the development and research of health care strategies for people with dementia. The main goal to be reached is a satisfying quality of life in spite of a progressively deteriorating chronic disease at all stages of the disease.
Background and objectives

• Community-dwelling people with early-stage = a major target group for research at the DZNE Witten.

• Research interest: self-reports of community-dwelling individuals with dementia as expressed in scientific studies.

• Research questions:
  “What needs do persons with dementia living at home express?”
  “What are their subjective demands?”
  “What do they do to cope with their situation?”

• A systematic review of reviews.
Results: Incongruity in perspectives

Some of the included reviews contain evidence of incongruities in the perspectives of PwD and their spouse, the family caregiver or professional carers (Ablitt et al. 2009, Braun et al. 2009, de Boer et al. 2007, Steeman et al. 2006).

Range of topics of the primary studies where incongruities were found:


- Impact of dementia on **marital relationship and couplehood** (Gallagher-Thompson et al. 2001, Wright 1991)

- **Quality of Life** of the PwD (Dröes et al. 2006, Sands et al. 2004)

- **Service preferences** and desired **outcomes of health care services** (Gwyther 1997, Bamford & Bruce 2000)
Results:

Incongruity in perspectives

„perceived incongruity“ & „measurable incongruity“
Dealing with and awareness of memory problems:

„Well, it is not really that I can tell the difference, it has more to do with what other people have observed. After all, my experiences still indicate that I am not very different from before.“ (Robinson 2000, p. 15)

- Experience of being accused of something of which the person him or herself is unaware.
- Lapses in memory are often only reflected by the partner/family.
- Partners/family serve as a reinsuring instance.

(Robinson 2000, Macquarrie 2005)
Making sense and coming to terms with the disease:

„I don‘t know what constitutes Alzheimer‘s, that is in the sense that it‘s obvious to other people, or obvious to yourself?“

- Discrepancy between the inner experience of the disease and the information the person receives regarding his or her condition.
- This discrepancy makes the information received ambiguous and incomprehensible, since it does not comply with the own experience.

(Phinney 1998, p. 12)
Relationship Quality:

• There seems to be more incongruence in relationships afflicted with dementia (even in the earlier to middle stages) than between healthy couples.

• PwD (male and female) tend to perceive marital quality and tension more positive than their partners.

• Reported coping strategies in tense situations differ between healthy spouse and PwD → Self-control/suppression vs. walking away/downplaying.

(Wright 1991)
Gender differences:

Male PwD

• Male afflicted/female caregiver dyads incongruent regarding: tension and sexual issues (Wright 1991).
• Male afflicted spouses tend to over-report frequency of sexual contacts (Wright 1991).
• Rapport-building approaches are high in husbands with AD but low in caregiver wives (Gallagher-Thompson et al. 2001).

Female PwD

• Female afflicted/male caregiver dyads incongruent regarding: instrumental issues and the total marital relationship (Wright 1991).
• Afflicted women perceive tension more accurately than afflicted men (Wright 1991).
Informal caregivers (spouse or other family caregiver) rate QoL lower than the afflicted person him- or herself.

Discrepancy was low, when PwD showed high depression scores.

Discrepancies are not influenced by severity of dementia/MMSE score.

Low ratings by caregivers are associated with high depression scores in the caregiver and high caregiver burden rather than with patients functioning or challenging behavior.

(Sands et al. 2004)
Determining domains of QoL: the perspectives of PwD vs. those of professional cares

- High differentiation of types of social contacts that have an importance for QoL.
- Sense of aesthetics in the living environment.
- Feeling of guilt in the domain affect.
- Attachment, social contact, enjoying meaningful activity and satisfaction with financial situation are important domains for PwD but are missing in several measuring instruments.

(Dröes et al. 2006)
Preferences concerning outcomes of (community) care:

• While informal carers are positive about the activities and stimulation provided, service users criticize them e.g. for being boring (Bamford & Bruce 2000).

• Feeling financially secure is a relevant outcome for PwD, but is not mentioned as a desirable outcome by carers (Bamford & Bruce 2000).

• Feeling safe and secure (fear of crime) maximising a sense of safety (need expresses by PwD) vs. reducing levels of anxiety and agitation (focus of carers) (Bamford & Bruce 2000).

• Further valued outcomes from the PwDs point of view: recognition of symptoms and receiving a diagnosis, participating in research (Gwyther 1997).
Conclusions

• PwD are able to express their subjective needs, demands and expectations.

• Views and priorities of carers and PwD sometimes differ significantly – proxy answers are a controversial issue (high chance of several bias!)

• The assessment instruments available seem to be insufficient to measure subjective needs and demands of PwD in their whole range – mixed methods designs might be an answer.

• The positive attitude of PwD is a valuable resource and should be addressed in the development of care structures and tailor made interventions for individuals and for couples.

• Further research is needed with regard to the needs and demands of different sub-groups of PwD and their families.
Dziękuję bardzo za uwagę!
Thank you very much for your attention!

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