Care for People with Dementia in the Community – The DEMNET-D-Study*


* funded by the German Federal Ministry of Health
Care of People with Dementia in Germany

- change in demographic structures worldwide
- risk of care-dependency rises (Döhner & Rothgang 2006)
  - 2.5 mio. people with care-dependency in Germany (Stat. BA 2011)
- increase of age-related illnesses and multimorbidity (Wurm & Tesch-Römer 2006)
- dementia is the most frequent neuropsychiatric disease in old age (Weyerer 2005)
- people with dementia (PwD): 2008: 1.1 mio. → 2050: 3.0 mio. (Bickel 2012)
Care of People with Dementia in Germany

- the care of PwD by different health care providers is a complex task (Reichert / Roth 2004)
- great efforts are directed to support PwD and their relatives in their own living arrangements
- shared care organized by networks becomes more important in the German health care system (Schäfer-Walkman / Deterding 2010)

shared care is a long-term cooperation of health care providers, services are tailored to certain target populations (Kofahl et al. 2003)
Care of People with Dementia in Germany

Dementia care networks (DCN) in Germany

- are local associations of different stakeholders (community care services, medical doctors, therapists, hospital facilities, self-help organizations, local authorities, etc.)
- are engaged in providing multiprofessional care and support for PwD in the community
- are not implemented systematically or nationwide
- differ regionally
- are very heterogeneous

Empirical findings about of DCN are lacking!
Objectives of the Study

- to survey characteristics and structures of DCN all over Germany in order to

- to describe (the course of) social and care-related situations of PwD being served by DCN

★ 4 research partners
◆ 13 Dementia Care Networks
Method

- structured interviews and archival analysis to evaluate characteristics of DCN
- longitudinal design (2012-2015) using face-to-face interviews with PwD and their family members to evaluate health-related outcomes and burden of care
- baseline: January – August 2013
- follow-up: January – August 2014
- ethical approval by the Ethics Committee of the University of Greifswald
Inclusion criteria

- persons with a medical diagnosis of dementia (PwD)
- dyad of PwD and his/her primary caregiver (e.g. family member)
- PwD is living in his/her own domesticity and not in institutional care arrangements
Primary Outcomes

**Quality of life** – QoL-AD *(Logsdon et al. 1999)*
- self- / proxy-rating: 13 dimensions (e.g. *family, health*)

**Social inclusion** – SACA *(Solomon et al. 2010)*
- self-rating: e.g. I feel accepted, when attending activities in the community.

**Remaining in own domesticity**

**Secondary outcomes:** Challenging behaviour (CMAI), nutrition (MNA), activities of daily living (IADL), severity of dementia (FAST), depression (GDS)
13 DCN, covering an area with about 5 mio. inhabitants
- 8 DCN in urban and
- 5 DCN in rural areas

DCN are governed by
- medical professionals,
- nursing professionals
- voluntary workers
# Baseline Results - Sample

<table>
<thead>
<tr>
<th></th>
<th>total (n=560)</th>
<th>urban DCN (n=290)</th>
<th>rural DCN (n=270)</th>
<th>group differences</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>female</strong></td>
<td>58.1% (n = 322)</td>
<td>58.2% (n = 166)</td>
<td>58.0% (n = 156)</td>
<td>p = 1.000*</td>
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<tr>
<td><strong>age in years</strong></td>
<td>79.5 (SD 8.6)</td>
<td>80.3 (SD 8.7)</td>
<td>78.6 (SD 8.5)</td>
<td>p = 0.023**</td>
</tr>
<tr>
<td>care-dependency level</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>p = 0.148***</td>
</tr>
<tr>
<td>(median, 1-3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>severity of dementia</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>p = 0.001***</td>
</tr>
<tr>
<td>(median)</td>
<td></td>
<td></td>
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<tr>
<td>living with family</td>
<td>55.7% (n = 312)</td>
<td>54.5% (n = 158)</td>
<td>57.0% (n = 154)</td>
<td>p = 0.301*</td>
</tr>
<tr>
<td>members</td>
<td></td>
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</tbody>
</table>

* Fisher`s exact test, ** t-test, *** Mann-Whitney U
Baseline Results – Primary Outcomes

- **Quality of life (proxy) (13-52)**
  QoL-AD: mean 28.6 (SD: 5.5)
  → moderate quality of life
  → no differences between urban and rural DCN

- **Social inclusion (8-32)**
  SACA: mean 24.4 (SD: 4.2)
  → well included
  → no differences between urban and rural DCN

- All participants live in their own domesticity
Baseline Results – Secondary Outcomes

- **Challenging behaviour** (CMAI)
  76.9% (n = 422) of PwD show at least one challenging behavior

- **Nutritional status** (MNA-SF)
  71.5% (n = 288) of PwD show a (risk for) malnutrition

- **Activities of daily living** (IADL, 0-8)
  severe impairment (mean 2.0; 1.9 SD)

- **Depression** (GDS)
  34.1% (n = 119) of PwD show mild to severe symptoms of depression
Conclusion

- DCN in Germany mostly care for PwD with severe dementia and various impairments (e.g. IADL, malnutrition, challenging behavior)
- BUT: reported QoL and social inclusion is still high
- results will shed some light on the question how to improve care and social participation of PwD
- Upcoming: evaluation of quality of life, social inclusion and the remaining in own domesticity in relation to patterns of use of DCN in the long run
DemNet-D:

Ahlener System
Arnsberger Lernwerkstatt
Demenzfreundlich! Treptow-Köpenick
Demenzfreundliche Kommune Charlottenburg
Demenzfreundliche Kommune Lichtenberg
Demenznetz Aachen
Demenznetz Düsseldorf
Demenznetz Teltow/Fläming
Demenznetzwerk Krefeld
Demenznetzwerk Memoclinic
Demenznetzwerk Minden/Lübbecke
Demenznetzwerk Uckermark
QVNIA e. V. Berlin-Pankow

Thank you for your attention!