Alzheimer Europe

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ACTIFCARE COHORT STUDY

Access to timely formal care
Overview

- **RQ1**: Factors associated with the use of formal care in general (Quantitative data)
- **RQ2**: Factors associated with the use of specific formal care services (Quantitative data)
- **RQ3**: Experiences and attitudes towards care of people with dementia and their carers relating to utilization or non-utilization of formal care (Qualitative data)
Design

- Longitudinal 1 year cohort study
- Fifty dyads per country (8 countries)
- **Inclusion: not (yet) using formal care**
- 3 assessments
- Variety of questionnaires

Main outcomes
## Demographics person with dementia

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<thead>
<tr>
<th></th>
<th>Total N= 451</th>
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<tbody>
<tr>
<td>PwD male (n, %)</td>
<td></td>
<td>MMSE score 0-30 (mean)</td>
<td>19 (range 3-30)</td>
</tr>
<tr>
<td>PwD age (mean)</td>
<td>207 (46)</td>
<td>CDR 0.5(n,%)</td>
<td>9 (2%)</td>
</tr>
<tr>
<td>Range</td>
<td>77.4</td>
<td>CDR 1 (n,%)</td>
<td>345 (75.5%)</td>
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<tr>
<td>PwD education (mean years)</td>
<td>9.8</td>
<td>CDR 2 (n, %)</td>
<td>87 (19%)</td>
</tr>
<tr>
<td>Marital status (n,%)</td>
<td></td>
<td></td>
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<tr>
<td>Married /Partnership</td>
<td>325 (71.7)</td>
<td></td>
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<tr>
<td>Widowed</td>
<td>109 (24)</td>
<td></td>
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<tr>
<td>Single/Divorced/Separated</td>
<td>19 (4.3)</td>
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<tr>
<td>Living together with carer(n,%)</td>
<td>325 (72)</td>
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# Demographics informal caregivers

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<table>
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<tbody>
<tr>
<td><strong>Caregiver male (n,%)</strong></td>
<td>151 (33)</td>
</tr>
<tr>
<td><strong>Caregiver age (mean)</strong></td>
<td>66.4</td>
</tr>
<tr>
<td><strong>Range</strong></td>
<td>[25-92]</td>
</tr>
<tr>
<td><strong>Caregiver education (mean years)</strong></td>
<td>11.91</td>
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<tr>
<td><strong>Caregiver relation (n,%)</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>290 (64)</td>
</tr>
<tr>
<td>Child</td>
<td>137 (30)</td>
</tr>
<tr>
<td>Other</td>
<td>44 (6)</td>
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</tbody>
</table>
Definition of service use

- Formal care services only
- 4 clusters:
  1) home care (social)
  2) home care (personal)
  3) daycare
  4) admission
- Care transitions
RQ1: Factors associated with the use of formal care in general
Basic model

RQ1

CDR (severity)

Needs

Formal care use
Method

RQ1

- Logistic regression
- Baseline predictors (variety of dyad variables)
- Dependent variable: formal care at FU1 and/or FU2
Significant predictors for access to care

RQ1

- Person with dementia:

  Living situation

  Physical Self Maintenance Scale score

  Instrumental Activities of Daily Living score
Significant predictors for access to care

RQ1

- Informal caregiver:
  
  *Education*
  
  *Visiting a support group*
Differences in care use between regions

RQ1

- Formal care use is lower in the south compared to the middle regions 
  \( B=-.921, p=.001, \text{Exp}=.398 \)

- Formal care use is lower in the south compared to the northern regions 
  \( B=-2.058, p=.000, \text{Exp}=.128 \)

- Formal care use is higher in the northern compared to the middle regions 
  \( B=1.176, p=.000, \text{Exp}=3.241 \)
Conclusion analysis

RQ1

- People with dementia who are living alone have better access to care
- Higher educated informal carers who visited a support group have better access to care
- Dyads living in the North of Europe have better access to care
RQ2: Factors associated with the use of specific formal care services
Specific care clusters: home social care

RQ2

- Significant predictors for home social care:

  PSMS (Physical Self Maintenance Scale) score
Specific care clusters: home personal care

RQ2

- Significant predictors:

  Sum of needs

  Age informal carer

  PSMS (Physical Self Maintenance Scale) score

  Region of residence
Specific care clusters: daycare

RQ2

- Significant predictors for Daycare:

  Sum of needs

  Person with dementia living situation

  Gender informal caregiver

  Visiting a support group

  Region of residence
Specific care clusters: admission

RQ2

- Admission to care home/hospital

- Significant predictors:
  
  *CDR (disease severity)*

  *Perseverance time*

  *Region of residence*
Conclusion analysis

RQ2

- Different predictors for different care clusters
- Important to keep this in mind while providing advice
RQ3: Experiences and attitudes towards care of people with dementia and their carers relating to utilization or non-utilization of formal care.
In-depth interviews

RQ3

- 80 In-depth interviews at FU2

- Step 1:
  Country-specific analyses
  inductive qualitative content analysis

- Step 2:
  Cross-national analysis
  summarize and synthesize the findings
A) Did receiving a dementia diagnosis influence the process of access to care? RQ3

- Practical advice

IE: “Nobody sort of sat you down and said, “Well this is what’s going to happen.’ No, I didn’t find him helpful.”

IT: “I missed a list where I could found exactly written which [services] I could have had access to”
A) Did receiving a dementia diagnosis influence the process of access to care? RQ3

- Focus on physical needs
- Barriers/ Facilitators
Conclusion analysis

RQ3

- Lack of information, lack of knowledge about available services, Key contact person is important

- Attitudes towards care usually shift as the severity increases
Conclusion analysis

RQ3

- Social network can postpone formal care
- Take needs into account when finding the right type of care
- Be proactive as a carer
What’s next?

- Follow-up at 3, 4 and 5 years
- Actifcare 2?
Thank you for your attention!