Access to timely formal care

Frans Verhey
Marjolein de Vugt
Claire Wolfs
Ron Handels
Liselot Kerpershoek
On behalf of Actifcare study team
Benefits of early diagnosis

- Needs can be met by care and support services,
- Caregivers receive timely support
- Lessened anxieties when informed
- A better chance of benefiting from treatment
- Opportunity to participate in decisions about care
But... there is a mismatch between Needs and Use of Formal Care Services

- 33-50% of PwD/ caregivers are not using the support services they need
- Half of those using services felt that they had no choice

Paradox

⇒ Rejected in early stages
⇒ Regretted in later stages

Brodaty, 2005; Wolfs 2012; Boots 2014
Germany
Gabriele Meyer
Ireland
Kate Irving
Italy
Orazio Zanetti
Netherlands
Frans Verhey, Marjolein de Vugt
Norway
Geir Selbaeck
Sweden
Anders Wimo
Portugal
Manuel Gonçalves Pereira
UK
Bob Woods, Martin Orrell
Decision making on access to formal care

- Rational decision-making
  - *Contradiction in terms*

- Complex
  - strong emotional process
  - difficulty accepting dementia
  - progressive nature of dementia
  - reliance on surrogate decision-making

Better understand the reasons for the mismatch between the need for and use of formal care services
Aim Actifcare

Better understand the reasons for the mismatch between the need for and use of formal care services

Organizational/ policy level

Level of PwD and Caregiver

Level of costs and consequences
Aim Actifcare

Better understand the reasons for the mismatch between the need for and use of formal care services

Organizational/policy level

Level of PwD and Caregiver

Level of costs and consequences

Best practice
Methodology

- **Mix of methods**
  - Literature review, focus groups, expert consultations
  - Quantitative cohort study
    - ± 50 dyads in each of participating 8 countries
  - Cost-consequence analysis

- **Theoretical Anderson model**
  - to assess the potential inequity of access to and utilisation of services
The Andersen Model of Health Care Utilization

Which **socioeconomic** and **cultural** aspects influence access to formal care?
Results form Literature Review:

Factors of influence on access to formal care

- Age
- Gender
- Family relationships
- Education
- Employment
- Urban vs. rural
- Ethnicity
- Financial aspects
- Attitudes towards dementia
- Attitudes towards care for people with dementia
Results
Literature on access to dementia care

**Age (DE, IE, IT, NL, UK)**

- Low influence
- Lack of services for early onset dementia
- Differences between services

**Gender (DE, IT, NL, NO, SE)**

- Male carers tend to use more services
Results

Literature on access to dementia care

Family Relationships (IT, NL, UK)

- Influence of family relationships unclear
- Spousal carers avoid involving other relatives into the caregiving situation.

Education (DE, IT, UK)

- Higher educated carers use services more intensively than lower educated carers.
Results

Literature on access to dementia care

Employment (DE, IT, SE)

- Employed informal carers need flexible services.
- Men less willing to accept occupational restrictions due to caregiving tasks, -> increased utilisation of services

Region of Residence (DE, IE, IT, UK)

- Difficulties in rural areas to find support services (except Nordic countries)
- Information and support services are situated predominately in urban areas.
Results

Literature on access to dementia care

**Ethnicity (DE, IE, IT, UK)**

- Inadequacy existing services for people from minorities/religious affiliations.
- ‘A family member with need of care should be cared for by the family’.

**Financial Aspects (DE, IE, IT, PT, SE)**

- Shame to ask for financial aid can be a reason for not accepting financial support.
- Most informal carers in Germany have to pay additional funds for support services.
Results

Literature on access to dementia care

Attitudes towards dementia (DE, IE, IT, UK)

- Anxiety, isolation and a lack of knowledge are barriers to utilization of formal care.

Attitudes towards care of people with dementia (DE, IE, IT, SE, NL)

- People with dementia prefer care from a relative.
- Informal carers describe negative feelings to use formal care for their relief.
- Lack of awareness for treatment options.
Which attitudes and beliefs do people have about Access to Formal Care

- Transnational focus group study
  - Individuals living with dementia
  - Informal carers
  - Healthcare professionals

- Eight European countries
# Focus Groups

<table>
<thead>
<tr>
<th>Focus groups, n (participants, n)</th>
<th>Total</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
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<tr>
<td>Healthcare professionals</td>
<td>20 (114)</td>
<td>4 (16)</td>
<td>3 (18)</td>
<td>2 (9)</td>
<td>2 (12)</td>
<td>2 (13)</td>
<td>2 (12)</td>
<td>2 (12)</td>
<td>3 (22)</td>
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<tr>
<td>People with dementia</td>
<td>14 (51)</td>
<td>3 (10)</td>
<td>2 (7)</td>
<td>2 (6)</td>
<td>2 (8)</td>
<td>3 (9)</td>
<td>1 (4)</td>
<td>-</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Informal carers</td>
<td>21 (96)</td>
<td>5 (21)</td>
<td>3 (16)</td>
<td>2 (8)</td>
<td>2 (10)</td>
<td>2 (7)</td>
<td>2 (11)</td>
<td>2 (8)</td>
<td>3 (15)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>55 (261)</strong></td>
<td><strong>12 (47)</strong></td>
<td><strong>8 (40)</strong></td>
<td><strong>6 (23)</strong></td>
<td><strong>6 (30)</strong></td>
<td><strong>7 (29)</strong></td>
<td><strong>5 (27)</strong></td>
<td><strong>4 (20)</strong></td>
<td><strong>7 (44)</strong></td>
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</tbody>
</table>

**Individuals living with dementia**: Mainly people in an early stage and early onset

**Informal carers**: Mainly women, diverse caregiving conditions

**Healthcare professionals**: Nurses, social workers, general practitioners, specialized physicians, case managers, counsellors, psychologists (mainly nurses in all countries)
Attitudes and beliefs from focus groups

System level
Aspects related to the health and social care system

Overarching aspects

Individual level
Aspects related to person involved
Attitudes and beliefs

Individuals living with dementia

- Threat to individual desire to stay independent
- Should be avoided at all events
- Want to be more involved in decision-making
- Limited recognition of their demands

“*They think us as worse than children (...) but it’s a mistake because we always carried on by ourselves until now and we’re doing it even now.*” (Person with dementia/Italy)
Attitudes and beliefs

Informal carers

- Predominately negative
- Dementia is still perceived as stigmatising
- Caregiving as obligation, relinquishing care as personal failure
- Meaning of caregiving for the families: e.g. giving something in return, fulfilling a promise

“To get someone in ... I would feel as if I was pushing him (the person with dementia) away.”

(Informal carer/UK)
Attitudes and beliefs

Healthcare professionals

- Perspectives of people with dementia reported sparsely ➔ Lack of insight
- Negative attitude

“Because of the media and even services are so much promoting independent living, it makes you feel like you failed basically ... a lot of guilt.”

(Healthcare professional/UK)
Summary Focus groups

Complex interplay of factors influencing access to care:

- Attitudes and beliefs
- Professional support seen as a threat to independence
- Lack of knowledge regarding dementia and available services
- Healthcare professionals function either as a barrier or a facilitator
- Constant contact person is widely lacking but may be a major facilitator
Cohort study

- **Inclusion criteria**
  - Dyad of PwD and informal carer
  - Person with dementia
    - CDR score 1 or 2 or < 24 score MMSE (focus middle stage)
  - Not receiving regular (>1/week) assistance from paid formal care at baseline

- **Baseline, follow-up assessments at 6 months & 1 year**

- **Individual interviews on experiences w/r Access to Formal care at 1 year**
Cohort study: current status

- 453 dyads completed at baseline
- Data collection finalized in Sept 2016
- Currently still analyzing
- Some provisional results
## Inclusion and loss to follow up

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<tr>
<th></th>
<th>NL</th>
<th>DE</th>
<th>UK</th>
<th>IE</th>
<th>SW</th>
<th>NO</th>
<th>PT</th>
<th>IT</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td><strong>Inclusion</strong></td>
<td>51</td>
<td>54</td>
<td>76</td>
<td>43</td>
<td>50</td>
<td>60</td>
<td>53</td>
<td>66</td>
<td>453</td>
</tr>
<tr>
<td><strong>Loss (%)</strong></td>
<td>19,6</td>
<td>11,1</td>
<td>26,3</td>
<td>27,9</td>
<td>14</td>
<td>18,3</td>
<td>16,9</td>
<td>19,6</td>
<td>16,7</td>
</tr>
<tr>
<td><strong>Passed away (%)</strong></td>
<td>3,9</td>
<td>9,2</td>
<td>5,2</td>
<td>6,9</td>
<td>2</td>
<td>1,6</td>
<td>5,6</td>
<td>1,5</td>
<td>5,7</td>
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</table>
# Individuals with dementia

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<thead>
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<tbody>
<tr>
<td><strong>N</strong></td>
<td><strong>453</strong></td>
</tr>
<tr>
<td>Women/ men (%)</td>
<td>54/46%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>77.4 [47-92]</td>
</tr>
<tr>
<td>Education (mean years)</td>
<td>9.8</td>
</tr>
<tr>
<td>Marital status (n,%), %</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>310 (68)</td>
</tr>
<tr>
<td>Widow</td>
<td>109 (24)</td>
</tr>
<tr>
<td>Single</td>
<td>8 (2)</td>
</tr>
<tr>
<td>Living together with carer (n,%)</td>
<td>325 (72)</td>
</tr>
<tr>
<td>MMSE score (mean)</td>
<td>19</td>
</tr>
</tbody>
</table>
Total number of unmet needs (CANE)

- Discrepancy among raters
  - Individuals with dementia 418
  - Informal caregivers 762
  - Actifcare researchers 846
Most frequent unmet needs

- **People with dementia**
  - company (15%), information (13%), and daytime activities (9%)

- **Informal carers**
  - daytime activities (28%), company (24%) and information (10%)

- **Actifcare researcher**
  - Same domains
  - Plus: psychological distress (14%) and finances (10%)
Factors from Cohort Study enhancing Service Use

- Dementia severity
- Hours spent to care by informal carer
- High number of both met and unmet needs
- Living situation
  - Children taking care
- High age and education of the person with dementia
- High carers’ Age, Education, Sense of coherence
Interviews:

Did formal care help staying independent?

- ‘Difficult question’, ambivalent
- Both barrier and enhancer
  - Threat to privacy and personal freedom (for both carer and pwd)
  - ‘you can do as much as possible for a longer time (with assistance)’
- Changing perspective
  - At first it seems like a limitation, but when formal care is in place, for most people this was an enhancement
Interviews:

Was the health care professional experienced as helpful?

- Often lack of knowledge about services
- A good explanation in the beginning is necessary (also leading to better insight)
- Take needs into account when finding the right type of care
- One contact person who is easy to reach is helpful
- Gradual start
Interviews

What would be your advice?

● Professionals should
  ➔ Better acknowledge the emotions of carer
  ➔ Should not be patronising.
  ➔ Should be trustworthy and respectful

● Be proactive as a informal carer yourself
Health Economy

- Country comparisons
- Explorative nature of analysis
  - cost-consequence analysis
- Validation of novel QoL instruments in dementia
  - ICECAP-O, CarerQOL
Mean annual costs per country in 2015 Euros
First provisional conclusions

- Room for improvement of access to formal care
- Attitudes overall rather negative
- Stigma on dementia/care
- Need for
  - empowerment of informal carers
  - care manager across care sectors
  - adequate information on services
  - more services in rural areas/ minority groups
Within next months we hope to:

- More in-depth analyses on access to European dementia care systems
- Gain more insight in health-economy effects
- Identify best practices strategies
  - to improve effectiveness and efficiency
- Compare care systems across countries
  - and learn from one another
The Actifcare team
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