

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



Total N= 451			
PwD male (n, %)	207 (46)	MMSE score 0-30 (mean)	19 (range 3-30)
PwD age (mean)	77,4	CDR 0.5(n,%)	9 (2%)
<i>Range</i>	[47-92]	CDR 1 (n,%)	345 (75.5%)
PwD education (mean years)	9,8	CDR 2 (n, %)	87 (19%)
Marital status (n,%)			
<i>Married /Partnership</i>	325 (71,7)		
<i>Widowed</i>	109 (24)		
<i>Single/Divorced/Separated</i>	19 (4,3)		
Living together with carer (n,%)	325 (72)		

Demographics informal caregivers

Caregiver male (n,%)	151 (33)
Caregiver age (mean)	66,4
<i>Range</i>	[25-92]
Caregiver education (mean years)	11,91
Caregiver relation (n,%)	
<i>Spouse/Partner</i>	290 (64)
<i>Child</i>	137 (30)
<i>Other</i>	44 (6)

Definition of service use

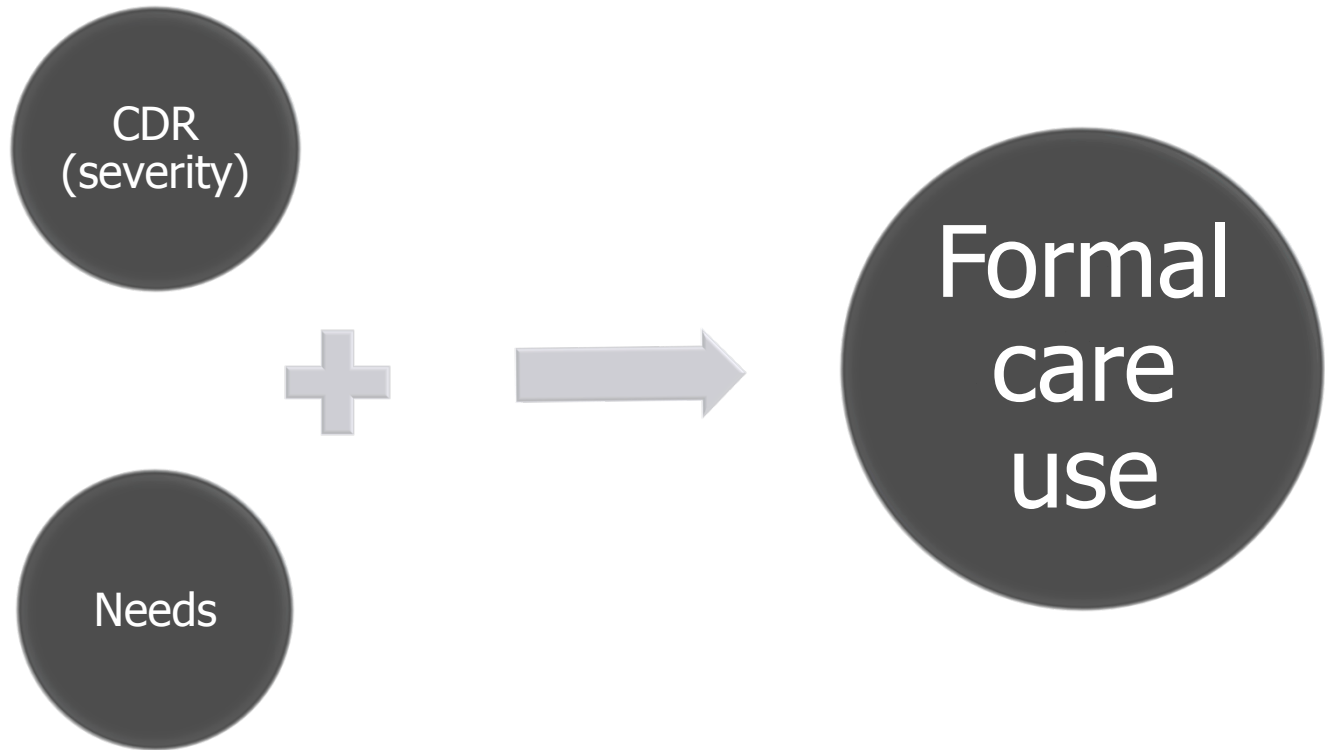


- Formal care services only
- 4 clusters:
 - 1) home care (social)
 - 2) home care (personal)
 - 3) daycare
 - 4) admission
- Care transitions

RQ1: Factors associated with the use of formal care in general

Basic model

RQ1



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
($B=-.921$, $p=.001$, $Exp=.398$)
- Formal care use is lower in the south compared to the northern regions
($B=-2.058$, $p=.000$, $Exp=.128$)
- Formal care use is higher in the northern compared to the middle regions
($B=1.176$, $p=.000$, $Exp= 3.241$)

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!

