



ActifCare

Access to timely formal care

**Utilisation of community care services
by people with dementia and their informal carers
in eight EU countries**

**Anja Bieber, Astrid Stephan, Anja Broda & Gabriele Meyer
on behalf of the ActifCare Consortium**

Background

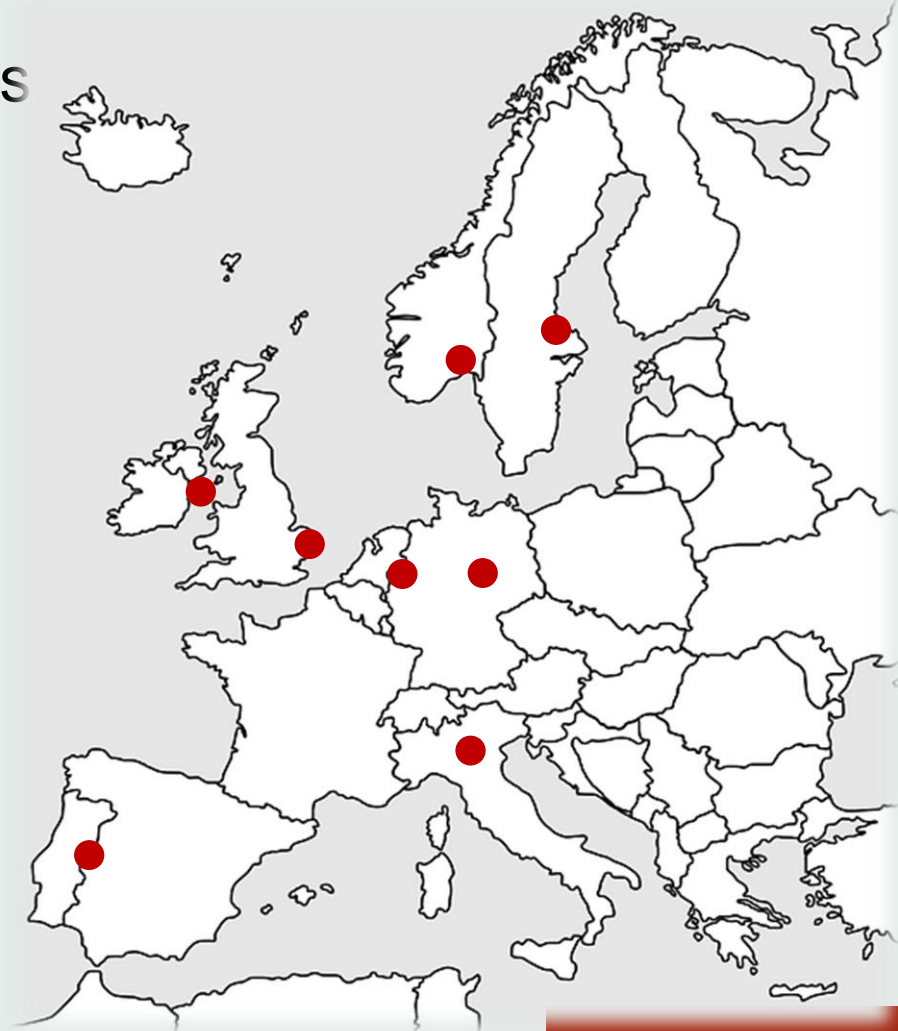
- People with dementia and their informal carers often hesitate to use professional support, even when they are in need of care
- Strain of caregiving and increasing need of care are predictors for transition to nursing homes
- Timely access to and utilization of formal care may stabilize the caregiving situation at home

Aim of the project

- Describing health and social care structures for accessing formal care
 - Identification of facilitators and barriers for utilization of professional help at home
 - Investigation of influencing factors and predictors
- **Development of best national practice recommendations**

Partners and Time Period

- Project partners from 8 countries
Germany, Italy, Ireland,
Netherlands (coordination),
Norway, Sweden, Portugal,
United Kingdom
- Time period 3 years: 01/2014-
12/2016 (in DE: 3/2017)



Project Plan



WP 1 (NL) Management

WP2 (DE) Access to services

- Systematic Review of predictors of utilization and description of national health care structures
- Focus group/ Expert interviews of barriers and facilitators in access to formal care

WP 3 (UK) Determinants for utilization of professional help

- Cohort study (one year, 3 interviews, 2015–2016)
- Single interviews (Dyads)

WP 4 (SE) Economic Evaluation

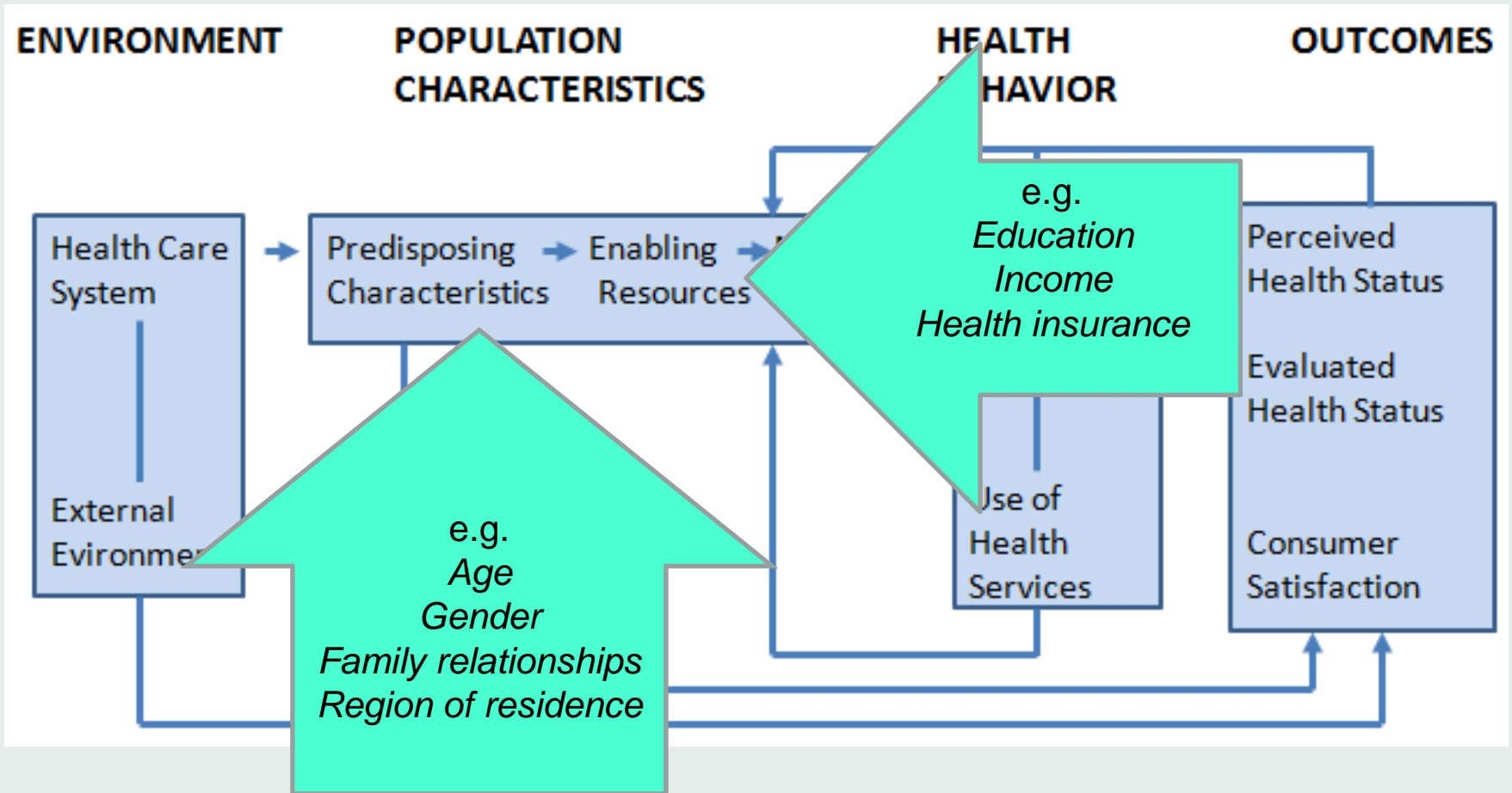
- Part of the cohort study (RUD)
- Analysis of cost-consequences

WP 5 (NO) Best practice strategies

- Overview of interventions, which aims to facilitate access
- Delphi-process
- Development of recommendations

WP 6 (IE) Dissemination

Andersen Model



Behavioral Model of Use of Health Services (Andersen, 1995)

Aim

Describing access to formal dementia care services throughout participating European countries.

Review

Which socioeconomic and cultural aspects influence access to formal care in the participating countries?

Methods



Data bases: PubMed, CINAHL, PsychInfo and Social Science Citation Index

Socioeconomic and Cultural Aspects:

- Age
- Gender
- Family relationships
- Education
- Employment
- Region of residence
- Ethnicity
- Financial aspects
- Attitudes towards dementia and care of people with dementia



Inclusion criteria

All study types

Topics: Investigating factors influencing *access to and use of community-based support services*

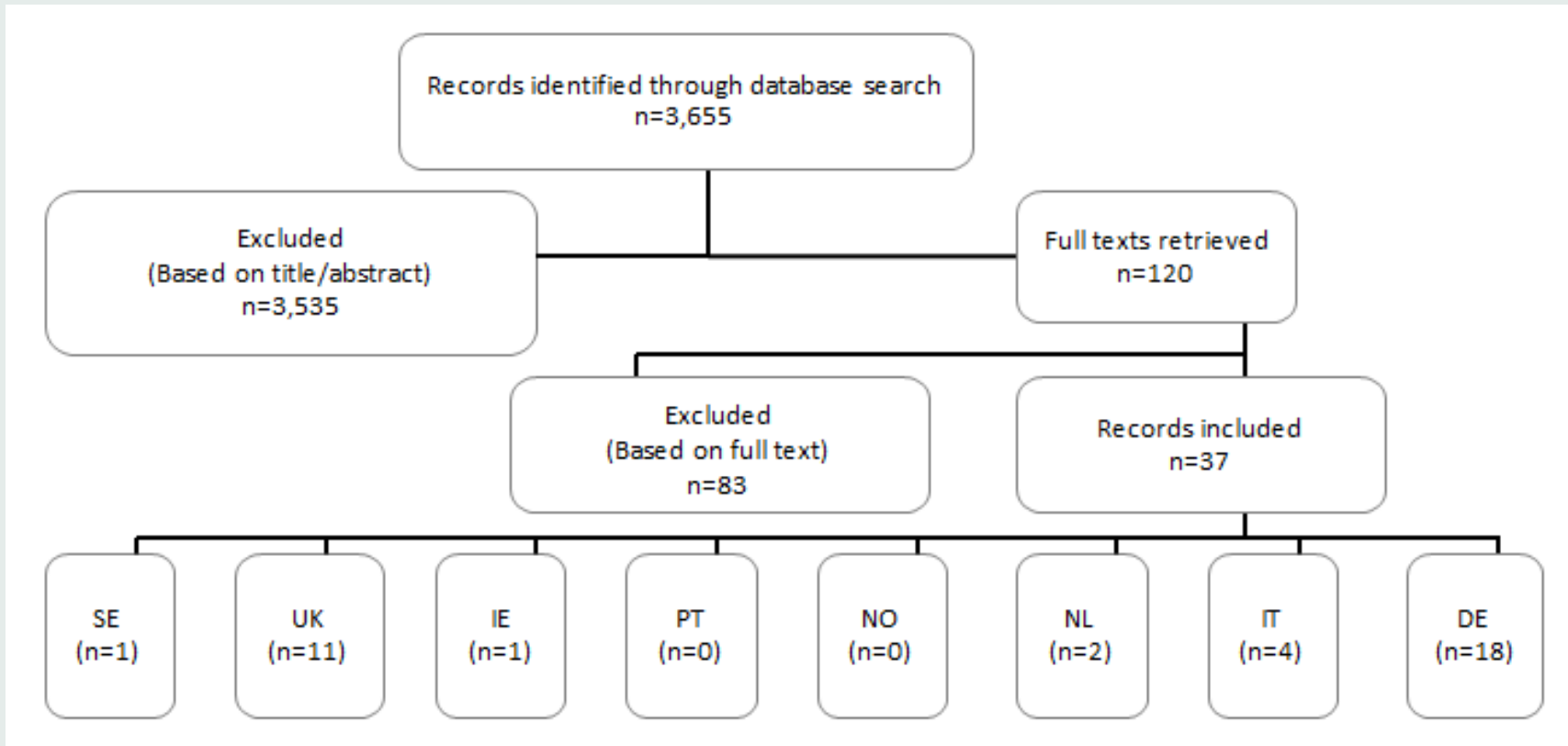
Population: People with dementia and informal carers

Setting: Community

Exclusion criteria

Studies which deal with medical diagnostic and pharmaceutical treatment only

Results



Results

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

Low influence

- No differences found in age between users of community care with and without dementia.

Differences between services

- Use of respite care and caregiver training increases with the age of the person with dementia.

Lack of services for early onset dementia

- Dementia care and services offered are generally within an older person's setting.

Results

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

Gender differences in receiving care in advanced dementia

- With advanced dementia, men receive more informal and formal care than women do.

Male carers tend to use more services

- Men use formal care for personal hygiene and domestic help more often than women.
- For female informal carers, it was easier to accept help on administrative and economic issues.

Results

Family Relationships (IT, NL, UK)

Influence of family relationships on access to and utilization of formal care is unclear

- Common attitude in Italy: Spouses are responsible for caregiving of their relative with dementia.
- Spousal carers usually avoid involving other relatives into the caregiving situation.

Results

Education (DE, IT, UK)

Only limited and inconsistent data available

- Differences in utilization of formal care by people with early memory problems cannot be explained with differences in education.
- EUROFAMECARE study: Higher educated carers use services more intensively than lower educated carers.

Results

Employment (DE, IT, SE)

Assumed impact of employment on utilization of formal care

- Employed informal carer need flexible services.
- Men were less often willing to accept occupational restrictions due to caregiving tasks, which led to increased utilisation of informal and formal support.

Results

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

The area of residence seems to be an important factor

- Additional difficulties in rural areas to find appropriate support services, with exception of the Nordic countries.
- Information and support services are situated predominately in urban areas.

Results

Ethnicity (DE, IE, IT, UK)

Additional barriers for carers with a migrant background

- Inadequacy identified of existing services for people from minorities or from differing religious affiliations.
- The informal carers confirmed that a family member with need of care should be cared for by the family.

Results

Attitudes towards Dementia and 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)

- People with dementia prefer care from a relative.
- Informal carers describe negative feelings to use formal care for their relief.

Results

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

Receiving of financial benefits

- A feeling of shame to ask for financial aid can be a reason for not accepting financial support.

Importance of out-of-pocket expenditures

- Most informal carers in Germany have to pay additional funds for support services.

Conclusion

- There is limited information available towards the influence of socioeconomic and cultural aspects of access to and utilization of formal dementia care for the participating countries.
- Further research should consider the complexity of influences in access to formal care.
- A scoping review is in process, which aims to chart the scope of research investigating a broad range of influencing factors.
- Analysis based on a version of the Andersen model adapted for long-term care.

ActifCare

Access to timely formal care



Thank you for listening!

Contact:
Anja Bieber

Martin Luther University Halle-Wittenberg
Medical Faculty
Institute for Health and Nursing Science
06108 Halle (Saale)
Germany
Tel.+49 345-557 4427
Mobil:+49 1575-2599641
E-Mail: Anja.Bieber@medizin.uni-halle.de
<http://www.actifcare.eu/>

