



IPA INTERNATIONAL PSYCHOGERIATRIC ASSOCIATION  
**International Congress**

13-16 October 2015

*Balancing Cure with Care: Advances in Late Life Mental Health*



**Actifcare**

# WORK PACKAGE 2

## ACCESS TO FORMAL CARE ACROSS EUROPE



MARTIN-LUTHER-UNIVERSITÄT  
HALLE-WITTENBERG

# AIMS

**1) Describing influencing factors**

**→ A scoping review**

**2) Describing facilitators and barriers**

**→ A cross-national focus group study**





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## 1) INFLUENCING FACTORS

PRELIMINARY FINDINGS OF A SCOPING REVIEW

# TITLE

**Factors related to the access and use of formal care  
of people with dementia and their informal carers:**

protocol for a scoping review  
and preliminary results

of a literature search for the Actifcare countries



*2015 IPA International Congress  
13-16 October – Berlin, Germany*

# BACKGROUND

- Diversity of influencing factors on the access to/use of long-term community services for people with dementia
- Andersen Model of Health Service Use provides the theoretical framework



# OBJECTIVE

To gain an overview of influencing factors on access to and use of formal care for people with dementia and their carers.



# RESEARCH QUESTIONS

1. Which influencing factors can be identified?
2. How can these factors be categorized?
3. What is known about the impact of psychosocial aspects?
4. Do these psychosocial factors correspond with the Andersen Behavioral Model by Bradley et al. (2002)?



# METHODS

## Comparison between systematic and scoping review (Armstrong et al., 2011)

Systematic review	Scoping review
Focused research question	Research question often broad
Inclusion/exclusion usually defined at outset	Inclusion/exclusion can be developed post hoc
Quality filters often applied	Quality not an initial priority
Detailed data extraction	May or may not involve data extraction
Quantitative synthesis often performed	Synthesis more qualitative
<b>Formally assesses the quality of studies and generates a conclusion related to the focused research question</b>	<b>Identifies parameters and gaps in a body of literature</b>





# SEARCH STRATEGY

## Information sources:

- PubMed
- CINAHL
- Social Science Citation Index
- PsychInfo
- Reports by the World Health Organisation, the Organisation for Economic, Co-Operation and Development, and the Alzheimer's Disease International

**Search terms:** dementia, formal dementia care, utilization/accessibility



# INCLUSION CRITERIA

## 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



# OUTCOME

## Classification factors according to the Andersen Model

**Psychosocial factors:** Attitudes, knowledge, social norms, perceived control

**Enabling factors:** Availability of support, financial resources

**Need factors:** Objective/perceived



# PRELIMINARY RESULTS

Search for influencing factors according to the traditional Andersen Model

**Socioeconomic factors:** age, gender, family relationship, ethnicity, education, region of residence, employment, financial aspects

**Cultural factors:** attitudes towards people with dementia, attitudes towards care of people with dementia



# PRELIMINARY RESULTS

## Findings for the Actifcare partners

Records included                      n= 37

### Publication date

1997-2004:                              n=9

2005-2014:                              n=28



# Findings for the ActifCare partners

Socioeconomic factor	Findings
Age	Lack of services for younger people with dementia Service use of specialists decrease with increasing age
Gender	Wives less often use services than other informal carers
Region of residence	Barriers in rural areas
Ethnicity	Additional barriers, e.g. lack of special services
Employment	Supposed to influence on service use
Financial aspects	Private payments are barriers

No clear findings on the influence of social/ family relationship



# PRELIMINARY RESULTS

## Cultural factors

### Attitudes towards dementia

Barriers for appropriate care are anxiety, isolation, lack of knowledge and lack of awareness (Facing Dementia Study, 2005)

### Attitudes towards care of people with dementia

Lack of knowledge of available support services (EUROFAMECARE , 2006)



# PRELIMINARY RESULTS

## Findings for the Actifcare partners:

Only few and partially inconsistent data were available, no studies in NO and PT

## Scoping review:

To gain an overview of influencing factors discussed in the international literature using the Andersen Model adapted for long-term care







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## FACILITATORS AND BARRIERS TO ACCESS

PRELIMINARY FINDINGS OF A FOCUS GROUP  
STUDY IN EIGHT EUROPEAN COUNTRIES

# METHOD

- Focus group study in 8 European countries (9/2014 – 4/2015)
- Experiences of people with dementia, caregivers and healthcare professionals regarding access and use of formal dementia care
- Sampling criteria: Experiences with formal care/healthcare professionals involved in providing access



# METHOD

- Questions focussing on barriers and facilitators
- Interview guide developed and consented by all partners, piloted in Germany
- Qualitative content analysis/open coding in each country
- Synthesis of the findings based on the country reports
- Analysis ongoing → Excerpt of first findings

# RESULTS

- n=55 focus groups with n=261 participants
- Duration ~90 min, groups with people with dementia shorter
- Difficult to include people with dementia (no group in SE) → people with early onset dementia overrepresented
- Healthcare professionals mainly nurses

# RESULTS

	Informal carers	People with dementia	Healthcare professionals
Groups n (participants, n)	21 (96)	14 (51)	20 (113)
Woman n (%)	77 (80)	28 (55)	97 (86)
Mean age, yrs. (range)	63 (37-91)	76 (54-96)	45 (23-62)
(Sub-)urban/rural	67/28	41/10	68/23*

Table 1: Participants' characteristics.

\* n=22 professionals worked in (sub-)urban and rural areas

# RESULTS

## Categories describing barriers and facilitators sorted to three global themes

- **Factors related to the individual level**
  - Aspects related to the individual situation/characteristics of people with dementia, caregivers or single healthcare professionals
- **Factors related to the healthcare system**
  - Aspects related to the health or social care system/organisational aspects
- **Overarching aspects**

# RESULTS - OVERVIEW

## Individual

### People with dementia and caregivers

- Knowledge and information
- Attitude towards dementia and formal care (in all countries!)
- Emotions
- Social environment/family structure and resources
- Trigger situations and personal motives

### Healthcare professionals

- Attitude and knowledge
- Social competences & strategies

## System

- Availability and features of services
- Complexity of the system – continuity (key contact person)

## Overarching

- Information
- Public awareness
- Early contact

# RESULTS

## ATTITUDE TOWARDS FORMAL CARE & DEMENTIA

### People with dementia

- Predominately reticent
  - Dementia is still stigmatising/scaring
  - Do not perceive their needs/lack insight into the disease
  - Professional support contradicts with desire to be independent
  - Connotations of formal care: written off/first step to care home
- Contrary: being open and seeking for information and support

*“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)



# RESULTS

## ATTITUDE TOWARDS FORMAL CARE & DEMENTIA

### Informal caregivers

- Predominantly reticent
  - Losing control, invading privacy
  - Do not perceive themselves as informal carers/help is normal
  - Denying problems, normalising the situation
  - Feeling obliged to care/give something in return → professionals support = personal failure, feeling guilty
  - Keeping it within the family → professional support = stigmatising
  - Stigma dementia
- Contrary: being open and seeking for information and support

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

# RESULTS

## ATTITUDE TOWARDS FORMAL CARE & DEMENTIA

### Healthcare professionals

- Accepting and respecting of the person with dementia
- Being open, neutral and tolerant - not patronising
- Valuing the knowledge if the IC
- Negative attitude towards dementia: no cure-less efforts, people are challenging (lack of knowledge and education), avoiding the diagnosis → stigma
- Social competences and commitment
- Relationship and partnership – not controlling

*“And that still happens sometimes in the care sector. [...] they (professional carers) enter private spheres where he/she [Persons with dementia] should still be in command and not be knocked down with a steamroller. I think that is a very, very important point.” (Social worker/Germany)*

# SUMMARY AND OUTLOOK

- Attitude seems to be important in all countries → predominantly reticent, dementia is still a stigma
- Professional support → contradictory to the independence of the people with dementia
- How to address attitudes (information, raising awareness)
- Promoting independence & better including people with dementia in decision making
- Analysis ongoing → comparison between countries and groups



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**THANK YOU FOR YOUR  
ATTENTION!**

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