

ActifCare

Access to timely formal care



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Transnational research project within the Joint Programme Neurodegenerative Disease Research (JPND)

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Barriers and facilitators of the use of formal care at home

Experiences of people with dementia, informal carers and healthcare professionals across eight European countries

Findings of a transnational focus group study.



Background



- Needs of people with dementia and their carers are complex and remain often unmet.
- Access to professional support is often initiated late in the progress of the disease.
- Timely access and utilization may prolong living at home.
- Research mainly focuses on reports of informal carers and correlational analysis based on observational studies.



Aims



- To explore the perspectives of all stakeholders involved in the process of accessing and using professional services.
- To identify barriers but also facilitators for the use of formal care at home.
- To provide an overview across eight European countries.



Method

- Focus groups in 8 countries (9/2014 – 4/2015)
- At least two focus groups per type
 - People with dementia
 - Informal carers
 - Healthcare professionals
- Criteria:
 - Having made experiences with professional support
 - Diverse types of health care professionals



Method

- Questioning route in all countries
 - Addressing barriers and facilitators
 - Developed within the consortium
- Qualitative content analysis (open coding) in each country
- Translation into English
- Synthesis of the national reports & discussion with partners



Participants

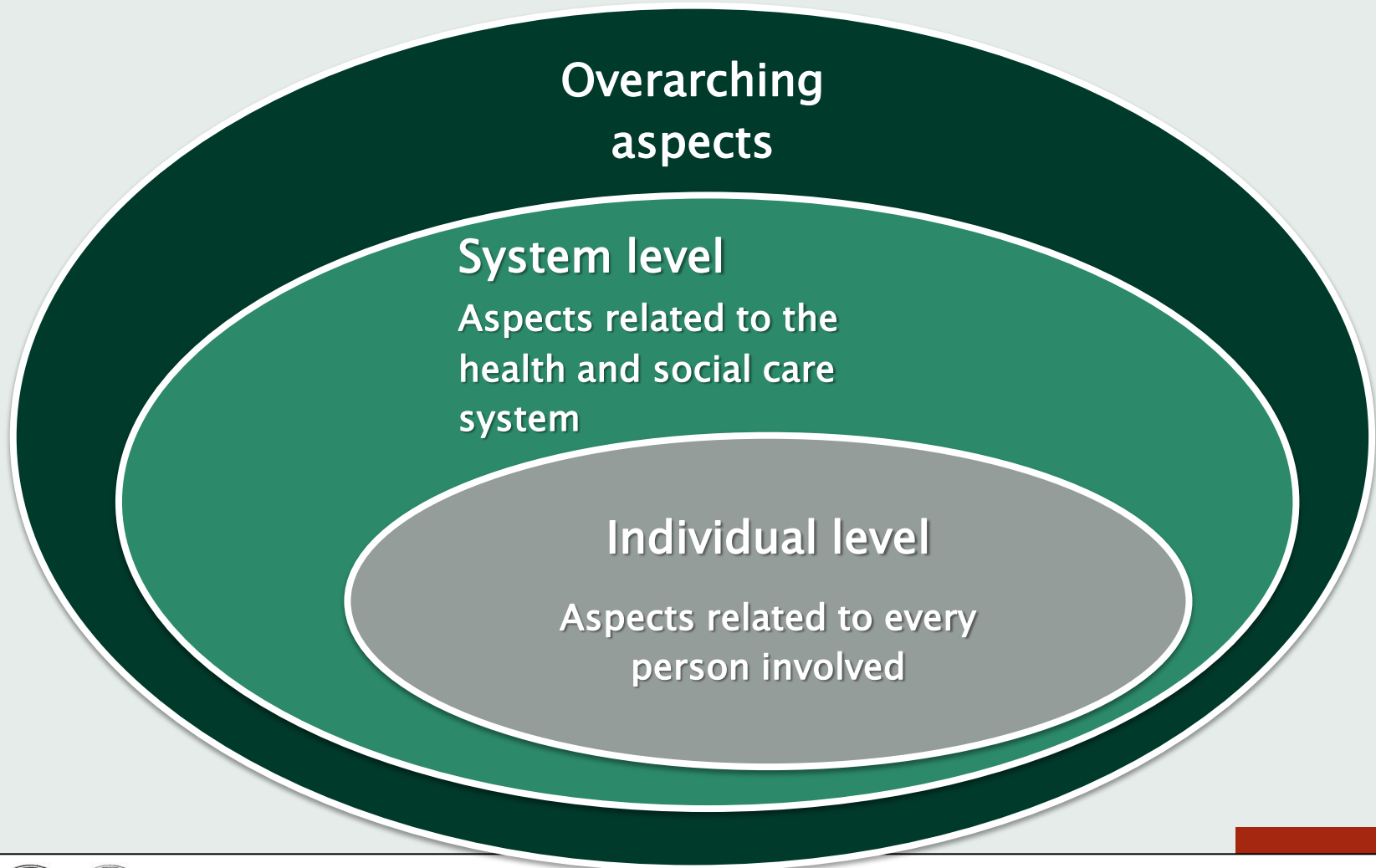
Focus groups, n (participants, n)	Total	DE	IE	IT	NL	NO	PT	SE	UK
Healthcare professionals	20 (114)	4 (16)	3 (18)	2 (9)	2 (12)	2 (13)	2 (12)	2 (12)	3 (22)
People with dementia	14 (51)	3 (10)	2 (7)	2 (6)	2 (8)	3 (9)	1 (4)	–	1 (7)
Informal carers	21 (96)	5 (21)	3 (16)	2 (8)	2 (10)	2 (7)	2 (11)	2 (8)	3 (15)
Total	55 (261)	12 (47)	8 (40)	6 (23)	6 (30)	7 (29)	5 (27)	4 (20)	7 (44)

Healthcare professionals: Nurses, social workers, general practitioners, specialized physicians, case managers, counsellors, psychologists (mainly nurses in all countries)

People with dementia: Mainly people in an early stage and early onset

Informal carers: Mainly women, diverse caregiving conditions

Findings



Findings

Theme	Categories (excerpt)
<p>Individual level</p> <p>–</p> <p>Aspects related to every person involved</p>	<ul style="list-style-type: none">• <u>Attitudes and beliefs of people with dementia and their informal carers regarding professional support (personal barriers)</u>• Personal motives and triggers for seeking and accepting support• Knowledge regarding dementia and available support services• Family structures and social context• Attitudes and competencies of the healthcare professionals (knowledge and social competencies and commitment)

Attitudes and beliefs

- In all groups, across all countries
- Predominately negative
- Dementia is still stigmatising

→ Informal carers:

- Professional support as stigmatizing
- Caregiving as an obligation → relinquishing care as a 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

→ People with dementia:

- Threat to the individual desire to stay independent and avoided at all events
- Being 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)

“Someone else (the children) must have found out what I needed”.
(Person with dementia/Norway)

Attitudes and beliefs



→ Healthcare professionals

- Perspectives of people with dementia reported sparsely → lack of insight and 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)



Attitudes and beliefs



- However, also triggers and motives clearly stated:

“For me it’s important that my children can carry on with their own lives. Well, of course, my children are looking after me and that’s nice, I’m always happy about that and so, but they can’t now, because I’ve got dementia or an Alzheimer diagnosis, and I don’t want that, that they can’t carry on with their own lives. That is really important for me.” (Woman with dementia/Germany).



Findings

Theme	Categories (excerpt)
<p>System level</p> <p>–</p> <p>Aspects related to the health and social care system</p>	<ul style="list-style-type: none">• Complexity and fragmentation• Lack of continuity and unclear structures (no „key contact person“)• Availability and features of services: tailored to the needs, particularly to social needs

“... those safe key boxes. Somebody recently said that they had given the number to 13 people. Now would you give that to...Would you give your number and the key access to your house to 13 people?” (Healthcare professional/Ireland).

Findings

Theme	Categories
Overarching aspects	<ul style="list-style-type: none">• Information• Public awareness• Early contact necessary – timely uptake of support is individual

“[...] regarding the accessibility of information, I’d say as a counsellor you are quasi in this pool of information in the network. You ask yourself all the time how is it that people in the end don’t find the information?”
(Healthcare professional/Germany)

Summary

Complex interplay of influencing aspects – key aspects

- Attitudes and beliefs of people with dementia and their carers
- Knowledge regarding dementia and available services (and their benefit)
- Professional (nursing) support is a threat to independence
- Healthcare professionals themselves may function either as a barrier or a facilitator
- Constant contact person is widely lacking but may be a major facilitator

Conclusion



How to change attitudes?

- Information, campaigns, mass media or movies?

How can professional support and nursing care better contribute to maintain independence?

- Involving informal carers and people with dementia in the development of services?

How to modify the health- and social care system?

- Better addressing social needs
- Enhancing continuity → establishing a constant contact person



Many thanks for your attention!

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