

Access to formal care: qualitative interview studies in eight European countries.

Findings of the Actifcare study



Actifcare

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Access to timely formal care

Background



- A number of influencing factors on the access to formal dementia long-term care have been suggested, findings are often contradictory (Neville 2015, Markle-Reid 2001)
- Qualitative studies only focus on the perspectives of family carers (Singh 2014, Peel 2014, Carpentier 2008)
- **A better understanding of the barriers and facilitators to use of services is required**

Aims



- I. Exploring the perspectives of all stakeholders involved in the process of accessing and using formal care and services**
 - people with dementia
 - family carers
 - health and social care professionals

- II. Exploring the perspectives of political decision makers/influencers on barriers and facilitators, seeking to identify possible solutions and strategies to overcome these barriers.**

Methods – *data collection*



Objective I

Focus groups in eight countries (9/2014 – 4/2015)

- At least two focus groups per type
 - People with dementia
 - Family carers
 - Healthcare professionals
- Criteria:
 - Having made experiences with professional support
 - Diverse types of participants/healthcare professionals country specific
- Semi-structured questioning route focusing on barriers and facilitators

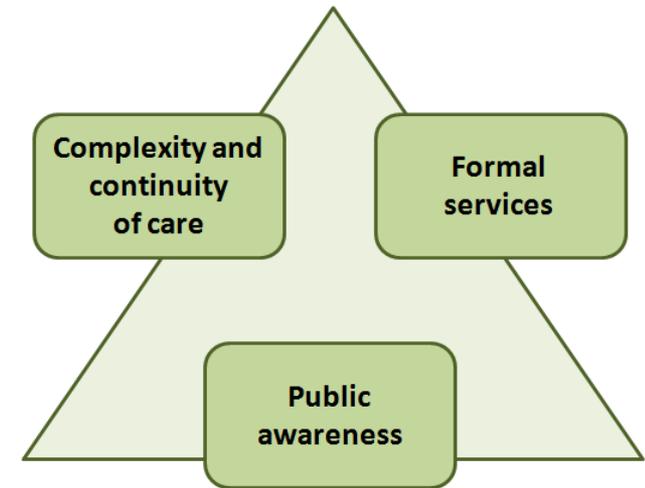
Methods – *data collection*



Objective II

Expert Interviews (9/2015 – 1/2016)

- At least 3-5 interviews per country (personal/phone)
- Criteria
 - influential in politics and decision makers
 - mainly on a national level
- Semi-structured interview guide focusing on
 - barriers and facilitators (considering the findings of the focus group study)
 - innovative ideas, strategies or suggestions how to structure and shape dementia care



Methods – *analysis*



Objective I & II

- Country-specific analysis of interview transcripts: inductive qualitative content analysis with open coding
- Cross-national synthesis focusing on similarities in themes and categories across the Actifcare countries

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)
Family 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 (41)	6 (23)	6 (30)	7 (29)	5 (27)	4 (20)	7 (44)
Expert interviews	Total	DE	IE	IT	NL	NO	PT	SE	UK
Participants	38	6	7	4	4	5	4	4	4

Findings: Overview



I Focus Groups

Overall, **16 categories** were identified, referring to three global themes:

Aspects related to

- 1) individuals involved
- 2) the system
- 3) overarching aspects

II Expert interviews

Overall, **10 categories** were identified, describing challenges and recommended strategies.

Findings: Focus groups



Individual level

- *Attitudes and beliefs* of people with dementia and their carers may have a major impact, often as barriers – but also strong motives are reported
 - Formal care was often perceived as a threat to the individual independence of people with dementia
- Professionals themselves and how they behave may also have a crucial impact

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

“For me it’s important that my children can carry on with their own lives.” (Person with dementia/DE)

“I think a lot of it is down to the communication style from our own sector, you know, meeting this individual in the home for the first time. Sometimes they are very fearful.” (Healthcare professional/IE)

Findings: Focus groups



System level

- A lack of need-oriented services and a complex system were considered as barriers
- A continuous key contact person was considered facilitating

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

Overarching aspects

- Information
- Raising public awareness
- Establishing early contact with people with dementia and their families

“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/DE)

Findings: Expert interviews



Characteristics of services

- *Client- or person-centred/tailored to the needs*
- *Multidisciplinary, counselling, proactive, low-threshold, flexible in terms of hours and schedules*
- *Early and escalating levels of support, 24/7 availability of services*

Coordinating role & role of the GP

“The most important thing is to have a single navigation point of a person: who can help you understand, who can interpret for you, the way in which the different parts of the system work together [...].”(UK)

Information

- *Providing websites and databases to inform about available services*

Networking/ cooperation

“You need systems where they are talking to each other.” (IE)

Findings: Expert interviews



Social inclusion

“The aim should not be to have services for people with or without dementia, the aim should be to have services for people in advanced ages.... We have to create normality here.” (DE)

Raising awareness/ dealing with stigma

➤ *E.g. involving prominent figures/celebrities and education (school, kindergarten)*

“People with dementia are seen as mad people. The dementia stigma persists as does the one about the psychiatric diseases.” (IT)

Resources/funding

➤ *Precondition*

Main Conclusions: Focus groups



- **A prerequisite for enhancing access:** *Understanding attitudes and beliefs*
- **Possible strong facilitators:** *A key contact person, establishing a continuous relationship, proactively & as early as possible*
- **Focused training for healthcare professionals:** *Their behaviour & competences serve as barrier or facilitator*

Main Conclusions: Expert interviews



- **Policy/political decision makers appear well acquainted with current discussions** among researchers and practitioners of approaches to improve dementia care
- Experts described **pragmatic, well-known and realistic strategies** to influence dementia care
- **Implementing** such approaches **remains a challenge**

Thank you for listening!



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