



# Family care for people with dementia: Empowerment and inclusion



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## Background and research question

Family Care givers are the most important group in the care for people with dementia (Small, Froggatt, Downs 2007; Kojer und Schmidl 2011). Being aware that care for and with people with dementia has to be supportive even in early stages of the disease a 3-days-training course based on Validation® according to Naomi Feil (Feil, De Klerk-Rubin, 2010; Fercher, Sramek 2013) has been offered for family care givers with their relatives with dementia. The aims of the presented study are to describe the effects of the training course for the relatives and to find out supporting factors for a "dementia friendly society". The research questions are:

- ♦ What are the effects of the training course based on Validation® concerning empowerment of family care givers for people with dementia?
- ♦ What kind of societal and structural environment in the community is needed to support participation of people with dementia and their family care givers?

## Methods

Within a participatory approach (v. Unger 2012) a research study encompassing one focus group with care giving relatives, 3 narrative interviews with families living with a person with dementia and 3 expert interviews, were conducted. Additionally typical situations of audio recordings taken during the training course were identified, transcribed and interpreted. A literature research and analysis was conducted in two phases during the project. Data were transcribed and analyzed thematically (Braun and Clarke 2006) in two stages: First in an individual process and then within the interdisciplinary research team.

Method	period	number
Focus group with family carers	September 2013	1
Interviews with family carers	October-November 2013	3
Expert interviews	July-September 2013	3
Analysis of audio records	May-July 2014	3 days
Literature analysis	September 2013-October 2014	2 phases



Photographies: Karl Rittmann



## First Results

First results show that the training course based on Validation® had very positive effects for family care givers. Learning that the loved person suffers from dementia and understanding symbolic meanings of behaviors makes care giving easier. Cultivating communicative attitude and skills based on Validation® helps in everyday living.

The fact that the people with dementia themselves were cared for during the training course enabled family care givers to attend the course. This can be described as a key factor concerning the participation of people with dementia. In some situations this also has an effect on families talking about dementia in their community.



## Discussion

- ♦ The first results show that direct support for family care givers of people with dementia through training based on Validation® seems to be helpful support for everyday living with dementia.
- ♦ Breaking the silence that often is associated with dementia and talking about difficult and challenging experiences strengthens coping strategies. Empowering effects can be observed.
- ♦ Factors influencing a "dementia friendly society" are connected with a culture of sharing the experiences, relationships within the community and public offers of professional support.
- ♦ The course concept based on Validation® can be used as a model for other contexts. As a next step we will elaborate key elements for dissemination.
- ♦ The study and analysis of literature shows: More qualitative studies are needed.

## Literature

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 Video documentary of the 3-days-course 2012 - <http://youtu.be/Ozldxc5vchl> (in German)

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