



Empowerment of Family Care Givers Living with People with Dementia



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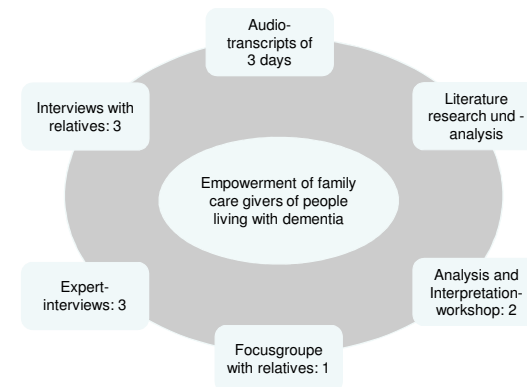
Background and questions

People living with dementia need support from relatives and family care givers as well as community support and adequate professional structures. Issues of palliative care such as loss and bereavement raise early in the course of disease (Small, Froggatt, Downs 2007; Kojer und Schmidl 2011). Being aware that care for and living with people with dementia has to be supportive especially in these 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 qualitative approach the study was conducted in participatory collaboration (v. Unger 2012) between University and the Austrian Institute for Validation. Data collection consisted of: 1 focus group with care giving relatives, 3 narrative interviews with families in presence of the person with dementia and 3 expert interviews. Typical situations of audio recordings taken during the training course were identified, transcribed and interpreted. A literature research was conducted. Data were transcribed and a two stage content analysis conducted: (1) an individual process and (2) within the interdisciplinary research team.



Results

The effects of the course based on Validation showed positive consequences for family care givers. The key factor enabling relatives to attend the course was the fact, the people with dementia themselves were invited and cared for during the course. Learning about dementia and practicing communicative skills based on Validation empowered family care givers for their everyday living.

Within the community, participation can be supported if relationships of long duration with neighbors are already established. It becomes difficult in places where public space for elderly people is scarce. In some situations talking about dementia in the community helps that people understand irritating ("challenging") behavior.

„Everybody knows about his dementia, and so it came that everything just grew slowly“

„The most important thing for me was to accept that this disease is just with us“



„My mom always wanted to go home,... And then I asked: who is your home, who is waiting there for you,..?“

„I just can take it easier now“

Discussion

- ◆ The training course based on Validation according to Naomi Feil offers helpful support for family care givers living with people with dementia. Empowering effects include breaking the silence that often is associated with dementia and talking about difficult and challenging experiences. Knowledge about the disease and communicative skills strengthen coping strategies. An appreciative attitude and empathy both well known also in hospice and palliative care makes relationships with people with dementia much easier.
- ◆ 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. Already existing initiatives in the context of „healthy communities" can serve as helpful social context. Regional aspects have to be taken into account.



Photographies: Karl Rittmann

Literature

Feil, Naomi; De Klerk-Rubin, Vicki (2010): Validation. Ein Weg zum Verständnis verwirrter alter Menschen. 9. Aufl., München: Ernst Reinhardt
Fercher, Petra; Sramek, Gunvor (2013): Brücken in die Welt der Demenz - Validation im Alltag. Reinhardt Verlag: München
Kojer, Marina; Schmidl, Martina (Hrsg.) (2011). Demenz und Palliative Geriatrie in der Praxis. Heilsame Behandlung unheilbar dementer Menschen. Wien: Springer.
Small, Neil; Froggatt, Katherine & Downs, Murna (2007). Living and dying with dementia. Dialogues about palliative care. Oxford: Oxford University Press.
von Unger, Hella (2012). Participatory Health Research. Who participates in what? [79 Absätze]. Forum: Qualitative Social Research, 13(1), Art. 7
Video documentary of the 3-days-course 2012 - <http://youtu.be/0zldxc5vchl> (in German)

Funding

The project was funded by the foundation for culture and science of the Carynthian trustee savings bank, Klagenfurt and the Austrian Ministry of Labour, Social Affairs and Consumer Protection

Acknowledgements

We thank all family care givers and the people with dementia for their time, confidence and reflections, Anna Hostalek, Karin Schönbauer, Alexandra Trafoier and Ilona Wenger for their administrative and research assistance

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Poster presented at the EAPC Congress for Palliative Care, Copenhagen, 8.-10. May 2015