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## Social Participation and Quality of Life in Dementia

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## Summary

The number of people with dementia is growing and according to Alzheimer's Disease International the worldwide prevalence of dementia will further increase in the coming decades. Dementia is a progressive syndrome, impacting among other things the emotional and social life of people living with it, and resulting in an increased dependency on informal carers and professional caregivers. Previous studies among people with dementia demonstrated that social participation is important for their quality of life. In this thesis the implementation and effects of two interventions are studied with a specific focus on enhancing social participation of people with dementia in order to promote their quality of life. The first intervention encompassed the transition of nursing home-based psychogeriatric day care for community-dwelling people with dementia to socially integrated community day care with carer support (CO day care, Chapters 2-5). The second intervention included the implementation of living room theatre activities for people with dementia (Chapters 6 and 7). Below, we summarize the results and conclusions (Chapter 8) from the studies in this thesis.

### **Chapter 2: Transforming nursing home-based psychogeriatric day care into socially integrated community day care with carer support: a process analysis**

The community-based Meeting Centres Support Programme for people with dementia and their carers has been proven more effective in influencing behaviour and mood problems of people with dementia and improving sense of competence of carers than nursing home-based day care centres for people with dementia. Six Dutch nursing home-based (NH) psychogeriatric day care centres were therefore transformed into community (CO) day care centres with carer support, according to this Meeting Centres model. In order to determine which factors facilitated or impeded the transition to CO day care a process evaluation was conducted by means of semi-structured interviews with 40 stakeholders and document analysis. The transition from NH psychogeriatric day care support to a CO combined support programme for people with dementia and their informal carer was shown to be feasible. Successful implementation of this CO combined support programme required motivated pioneers, a change in staff attitude and working style, a suitable pleasant location and collaboration with other care and welfare organisations. Barriers to implementation were insufficient involvement of, and support from the managers of the responsible organisations to facilitate staff during the transition process, and communication problems with referrers of other organisations, including the GPs and case managers.

### **Chapter 3: Effects of psychogeriatric community day care with carer support on people with dementia**

As part of the implementation study, we also conducted an explorative effect study in which we compared new participants (persons with dementia and their carers) of eleven community (CO) day care centres (experimental group, n = 70) with new participants in eleven traditional

nursing home-based (NH) day care centres (control group, n = 68) on quality of life and several quality of life related outcome measures at baseline and after six months. After six months we did not find statistically significant differences on needs, behaviour, mood or quality of life between these groups. However, subgroup analyses pointed out that after six months new participants of *recently started* CO day cares had less neuropsychiatric symptoms (medium effect size) than new participants of NH day care. Carers of people with dementia participating in the *longer existing* CO day cares reported fewer care needs of the person with dementia than carers of the control group (large effect sizes). People with dementia cohabiting with a carer particularly benefitted from CO day care, reporting less (un)met needs than the control group (large effect sizes). Because of the small statistical power and high drop-out rates, this study should be viewed as a first explorative study indicating an added value of CO day care compared to NH day care. Further research is recommended to investigate whether these effects can be replicated in a larger controlled effect study with more CO day care centres working according to the MCSP-model for a longer period.

#### **Chapter 4: Effects of psychogeriatric community day care with carer support on informal carers**

We also studied if there was an added value of community (CO) day care compared to nursing home-based (NH) day care with regard to needs, emotional burden and quality of life of informal carers. For this study, we included 67 informal carers of people with dementia who were new in eleven CO day care centres (experimental group) and 64 informal carers of people with dementia who started in eleven NH day care centres (control group). After six months, informal carers using CO day care expressed an unmet need for support regarding psychological distress more often than carers utilizing NH day care, while no differences were found regarding the objective burden or subjective burden between the carer groups. To explain the difference in expressed unmet needs it is suggested that carers using CO day care with carer support became more aware of their own needs for support because of the information they received and the contact with peers in the discussion groups. No differences between CO and NH day care were found on carers' sense of competence and quality of life. Subgroup analyses pointed out that carers participating in CO day care with a low sense of competence at baseline, were less emotionally burdened by behaviour and mood problems of their relative after six months as compared to carers who were involved in NH day care. Possible explanations suggested for not finding clear beneficial effects of CO day care on a group level are the high drop-out rates and low statistical power due to a small number of respondents, as well as the fact that the carer support programme was not yet fully operational in all CO day care centres during the study. We therefore recommend replicating the study in a randomized controlled trial with a larger sample of people with dementia and carers and CO day care centres where the support programme is successfully implemented.

**Chapter 5: Psychogeriatric community day care versus nursing home-based day care: a comparison of user satisfaction and job satisfaction of staff**

To investigate if community (CO) day care is associated with higher user satisfaction of people with dementia and their informal carers, we collected data among people with dementia (PwD) and their informal carers (CG) after six months of participation in eleven CO day care centres ( $n_{\text{PwD}} = 28$ ,  $n_{\text{CG}} = 36$ ) and eleven NH day care centres ( $n_{\text{PwD}} = 41$ ,  $n_{\text{CG}} = 39$ ). At the CO day care centres people with dementia were more positive about the communication and listening skills of staff and the atmosphere and activities at the centre than in NH day care. Also informal carers rated the communication with, and expertise of staff in CO day care higher, and were more satisfied with the received emotional, social and practical support. Job satisfaction was measured only in the six NH day care centres that recently transformed to CO day care, with two standard questionnaires before ( $n_{\text{STAFF}} = 35$ ), and six months after the transition ( $n_{\text{STAFF}} = 35$ ). After the transition, satisfaction of staff with the pace of work increased, but satisfaction with learning opportunities decreased. This explorative study indicates that this transition is positively valued by people with dementia, carers and professionals, and that sufficient learning opportunities should be provided to all staff members.

**Chapter 6: Implementing living room theatre activities for people with dementia on nursing home wards: a process evaluation study**

A new communication method, the '*Veder Method*', was implemented in 130 psychogeriatric nursing home wards in the Netherlands. This method uses theatrical stimuli in combination with the person-centred communication methods reminiscence, Validation and Neuro-Linguistic Programming. Care staff was trained to apply the Veder Method in a group activity ('living room theatre activity') for nursing home residents with dementia. Facilitators and barriers to implementation of the Veder Method (including staff training) on nursing home wards were evaluated by means of semi-structured interviews with 12 stakeholders five focus groups with 35 trained care staff. Respondents experienced the added value of the Veder Method in the positive reactions of residents and more reciprocity in caregiver-resident contact, which in turn motivated the trained care staff to apply the Veder Method. An action plan, executive support, the visibility of the method in the organisation and a pioneer group that initiated the implementation were essential for successful implementation of the Veder Method. An important barrier to implementation was that some managers did not allow the care staff sufficient time to prepare and execute the living room theatre activities and to attend the refresher days. High work pressure for care staff and insufficient training and coaching on the job also impeded the implementation. Insight in facilitators and barriers to the implementation of the Veder Method as provided in this study may help nursing homes determine an effective strategy for the successful implementation of the Veder Method.

## **Chapter 7: Does theatre improve the quality of life of people with dementia?**

In order to study the effects of a 'living room theatre activity' on behaviour, mood and quality of life of people with dementia, three groups of nursing home residents with dementia were compared on 22 wards in 13 nursing homes. The first group joined a living room theatre activity offered by trained caregivers (experimental group 1, n = 64), the second group joined a living room theatre activity offered by professional actors (experimental group 2, n = 31) and the third group participated in a reminiscence group activity offered by experienced caregivers (control group, n = 52). During and two hours after the intervention, small and medium positive effects were found in experimental group 2 on behaviour (e.g. laughing, recalled memories), mood (e.g. happy/content) and domains of quality of life (e.g. social involvement, feeling at home). No positive effects of living room theatre activities were found when offered by trained professional caregivers. On the contrary, we found some (small) negative effects on mood, behaviour and care relation compared to reminiscence group activities. This may have been caused by difficulties caregivers experienced in performing the theatre activity with the same quality and intensity as professional actors. All in all, the results of this first explorative effect study on living room theatre activities suggest that the performance of the living room theatre activity by professional actors had added value for people with dementia compared to the living room theatre activities and reminiscence group activities offered by trained caregivers. Further research, preferably randomized controlled trials with a larger sample size, higher power, and a longer follow-up is needed to confirm whether regular living room theatre activities offered by professional actors indeed have positive effects on behaviour, mood and quality of life of people with dementia, and to find out whether living room theatre activities performed by caregivers who are trained and experienced in conducting these activities have comparable positive effects on behaviour, mood and quality of life of people with dementia.

## **Chapter 8: General Discussion**

Chapter 8 contains a summary of our research. Furthermore, several methodological considerations, recommendations for future research, practice and policy are described.

One methodological strength of our studies into the implementation processes is that we used the Theoretical framework of adaptive implementation and the Implementation Process Evaluation (IPE) Framework, providing a structured and phased tool to investigate success and failure factors for implementation. A limitation of our study on CO day care is that we did not include measurements of reach (the degree to which the method reaches the target group) and treatment fidelity (the degree to which the intervention is implemented as intended). Limitations of the effect studies were a low statistical power due to small sample sizes, high drop-out rates and the timing of the outcome measurements (shortly after implementation).

Recommendations for future implementation research are to always perform process analyses alongside intervention effect studies in order to gain insight into facilitators and barriers to implementation, to include measurements of reach and implementation effectiveness to gain insight into treatment fidelity, and to give attention to continuation of the intervention. Another

recommendation is to develop more psychosocial interventions with a specific focus on enhancing social participation of people with dementia and to develop and include measurements of social participation in the effect studies on these interventions.

Although strong evidence is currently lacking because of study limitations, practical recommendations include the suggestion to consider the application of the studied interventions in individual cases because of the promising results on several quality of life-related outcomes in (subgroups of) people with dementia and carers, provided that correct execution of the interventions is ensured. Necessary preconditions for successful implementation of the interventions are described including the need for a dedicated project leader, an implementation plan, sufficient time to execute the intervention, and staff (re)training.

Policy recommendations include further investment in research on psychosocial interventions enhancing social participation of people with dementia and their carers to improve their quality of life, to ensure that good quality day care and support is accessible to all community-dwelling people with dementia and their carers, and to further invest in well-trained and skilled staff in day care centres and nursing homes, as well as in (the development of) meaningful activities that enhance social participation of people with dementia in nursing homes.