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REHABILITATION IN DEMENTIA

EXPLORING FEASIBILITY AND ADDRESSING LONELINESS

Josefine Lampinen

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Fakultetsopponent: Professor emerita, Louise Nygård
Institutionen för Neurobiologi, Vårdvetenskap och Samhälle,
Karolinska Institutet, Stockholm.

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Josefine Lampinen

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Abstract

The overall aim of this theses was to evaluate the feasibility of a person-centered multidimensional interdisciplinary rehabilitation program among community-dwelling adults with dementia and their informal caregivers, and to explore loneliness in adults with dementia.

Methods: For this thesis, data was utilized from a population-based study, the Umeå 85+/Gerontological Regional Database (n=1176) and a randomized controlled pilot study, the Multidimensional Interdisciplinary Rehabilitation in Dementia (MIDRED) study. Sixty participants with dementia and 66 informal caregivers in the MIDRED study were included in either a control group (usual care) or the rehabilitation program. Participants with dementia (n=16) and informal caregivers (n=14) from the MIDRED study were interviewed individually to explore their experiences.

Results: In Paper I, the prevalence of loneliness (often/sometimes) did not differ significantly between very old adults with (50.9%) and without (46.0%) dementia. Living alone and having depressive symptoms were associated with loneliness in both groups, while living in a nursing home was associated with less loneliness in those without dementia. Paper II revealed that the response rate was high for all assessments concerning mental health, loneliness, and social participation until the 12-month follow-up, including questions with multiple-choice alternatives. Overall, there were few statistically significant differences between the groups. However, some of the findings seemed potentially clinically meaningful in the areas of social participation and mental health (short-term). When exploring experiences of participation in the program, participants with dementia in Paper III described empowerment through participation and togetherness. Experiences of informal caregivers in Paper IV revealed themes of feeling challenged yet boosted, finding joy and frustration in supportive activities, and recognizing the relative's former self.

Conclusion: In very old adults, loneliness seems equally prevalent among those with and without dementia. The two groups shared two of the three factors associated independently with loneliness (living alone and having depressive symptoms). Living in a nursing home was associated with the experience of less loneliness in those without dementia. These findings contribute to important knowledge when developing strategies to reduce loneliness in this growing age group characterized by high risks of loneliness and dementia. Overall, the rehabilitation program for community-dwelling adults with dementia and their informal caregivers, seems feasible. The findings indicate that it is relevant to further proceed to an adequately powered RCT. To alleviate loneliness, one could consider to further develop the intervention.

Keywords

Aged, Dementia, Experiences, Feasibility study, Informal caregivers, Interdisciplinary rehabilitation, Loneliness, Mental health, Qualitative, Social participation

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