

“Familycare”: Insights to Evaluation Results of a Mobile Dementia Coaching for Informal Caregivers

Christine Pichler, Carinthia University of Applied Sciences, Austria

The European Conference on Aging & Gerontology 2024
Official Conference Proceedings

Abstract

Familycare is an evaluation-project of the mobile dementia coaching, which is offered by a social organization in Carinthia, Austria. The aim of the program is to relieve the burden on family caregivers of people with dementia, to educate them through knowledge transfer and to prevent health risk factors. The research design of the evaluation is based on a mixed-methods approach: descriptive-quantitative questionnaires and qualitative interviews were conducted with the target group. This conference paper presents the research design and the evaluation results. The research results show, that half of the people surveyed feel very or extremely burdened by caring. This is accompanied by a lack of information about the clinical picture of dementia and possible support services. The use of the coaching shows that almost 95% of the people surveyed stated that they found the service helpful or very helpful. Just as many people would recommend the service to others. The results also show that the coaching enables family caregivers to better understand the clinical picture of dementia and to better take on their own role as informal caregivers. It is possible to turn to the coaching team with questions, which on the one hand provides security and on the other hand gives the feeling that caregiving relatives are not alone, as the data shows. Self-care and setting boundaries are further things that family caregivers were able to learn through this coaching. The evaluation results thus confirm positive effects, which include reducing loneliness and promoting recognition for informal caregivers.

Keywords: Caring Communities, Dementia, Dementia-Inclusiveness, Participatory Approaches

iafor

The International Academic Forum
www.iafor.org

Introduction

This document presents the findings from an evaluation project of a mobile dementia coaching program for informal caregivers in Austria. The study utilized a mixed-methods approach, including questionnaires and interviews, to assess the effectiveness of the program in providing relief, knowledge, and health risk prevention for family caregivers. The results highlight the high burden experienced by caregivers, the benefits of the coaching program, and the importance of continued evaluation to measure long-term impacts.

Recent studies in Austria have found that family caregivers, particularly those caring for individuals with dementia, experience high levels of stress and burden. This underlines the critical need for support services and interventions to alleviate the physical and emotional strain on these caregivers (Nagl-Cupal et al., 2018). The Diakonie de La Tour recognized this issue and initiated a project in 2022 to introduce relief services and other measures to support family caregivers in the home setting in Carinthia, in the South of Austria. The aim of the scientific evaluation is to show to what extent this intervention is effective and what effects can be recognized with regard to the target group (Diakonie, 2022).

Objectives and Methods

The Mobile Dementia Coaching aims to provide relief and support for family caregivers through a variety of measures, including counseling, home-based training, and social integration. A key objective is to improve caregivers' knowledge and understanding of dementia and their caregiving role by providing information and resources. The project also seeks to help to prevent health risks and burnout among family caregivers by addressing their physical, emotional, and social needs (Diakonie, 2022).

To assess the effectiveness of this outreach-oriented intervention, the evaluation team is conducting a formative evaluation using an integrative research design. This mixed-methods approach includes three key modules: Descriptive-Quantitative Surveys, Caregiver Interviews and Result Reporting. Two questionnaires are being used to gather data from individuals who have accessed the Mobile Dementia Coaching service, both at their first and second appointments. Semi-structured interviews are being conducted with a sample of caregiving relatives participating in the program to gain deeper insights into their experiences. The integrative findings from the quantitative and qualitative data will be compiled into a comprehensive report to assess the overall effectiveness of the Mobile Dementia Coaching.

The first step was to carry out comprehensive research and review relevant survey instruments in the field of carers/caregiving relatives in order to record the current state of research. A comparison of existing instruments was also done. This provided important insights for the content and design of the questionnaire. As a result of this research, the questionnaire design was based on the following sources:

The Berliner Inventar zur Angehörigenbelastung-Demenz (BIZA-D) (Schacke & Zank, 2009) was developed as part of a large German longitudinal study on the burden on carers of relatives of dementia patients. It differentiates between objective and subjective stress as well as primary and secondary stressors. It also asks about the long-term consequences of care, coping strategies and support (Schacke & Zank, 2009).

The Zarit Burden Interview is a well-known instrument for self-reporting by family carers. The quality criteria of this instrument are suitable about a comprehensive view of the situations of family carers; it is used internationally to record the stress/burden of family carers. The number of items varies between the different versions of the instrument, which means that it can be customised to the research question (Mosquera et al., 2016).

The questionnaire for recording the situation of family caregivers (Nagl-Cupal et al., 2018) was created as part of research for the Federal Ministry of Labor, Social Affairs, Health and Consumer Protection in Austria and covers all important dimensions, such as socio-demographic characteristics, resources, prevalence, negative and positive aspects of care, etc., which are relevant in the course of the subject area of this evaluation research.

An initial version of both questionnaires for this accompanying evaluation was derived from the instruments listed above and adapted to the research question. The first version of the questionnaires was discussed with the client at the start of the accompanying evaluation in 2022 and adapted accordingly. In addition to content-related aspects, the focus was on making the questionnaires as inclusive and barrier-free as possible so that they could be completed by family carers, some of whom are under a great deal of strain, and so that they would not be overwhelming. The final version includes the following dimensions: Questions about the current care or caring situation, effects of care, offers, questions about the offer (only in questionnaire 2), as well as socio-demographic questions.

The quality of the questionnaire was tested by a pre-test and was available both in online format in Limesurvey and in paper-pencil format. The questionnaires were distributed to the clients by the staff of the service and returned to the research team.

The interview guide for the evaluation of the "Mobile dementia coaching" project was designed based on a comprehensive literature review on the topic of caring relatives and was based on the previously developed questionnaire.

The method "collect", "check", "sort" and "subsume" (Helfferrich, 2011, p. 182ff.) was used. In the first step, all questions that could be relevant for the evaluation of the project were collected. This included literature research on the topic of family carers of people with dementia, a reference to a pool of questions that were formulated in the course of creating the questionnaire but not used in it, as well as feedback and assessments from the client. In the second step, this collection of questions was reviewed and reduced according to its applicability and feasibility: Factual questions and monosyllabic questions were removed, the questions were checked for their openness and compared with the content of the quantitative questionnaire (Helfferrich, 2011, p. 182ff).

In the third step, the questions were sorted according to the topics relevant to the monitoring evaluation and the identification of effects. These include the current care situation, effects of care and questions about mobile dementia coaching. Thus, the four topic blocks recommended in the literature were not exceeded in the interview guide used. In the last step of the guideline creation, the topics were subsumed: The topic blocks each begin with open questions in order to provide a narrative impetus and to be able to give space to new aspects. This is followed by optional questions, which are only asked in greater depth or provide help for the interviewer if the open question alone does not lead to sufficient answers or important aspects are not mentioned in the context of the open question (Helfferrich, 2011, p. 181ff).

After pre-testing the employees of the programme provided access to the field to clients of the Mobile Dementia Coaching. The interviews were audio-recorded and then transcribed. The evaluation was carried out using Maring's summarising content analysis (Maring, 2022 & 2015).

Results

The first questionnaire, completed by 38 individuals accessing the Mobile Dementia Coaching service for the first time, revealed some key insights. Participants had varying levels of knowledge about dementia, with some reporting good awareness of the disease and available support services, while others had more limited understanding (Figure 1).

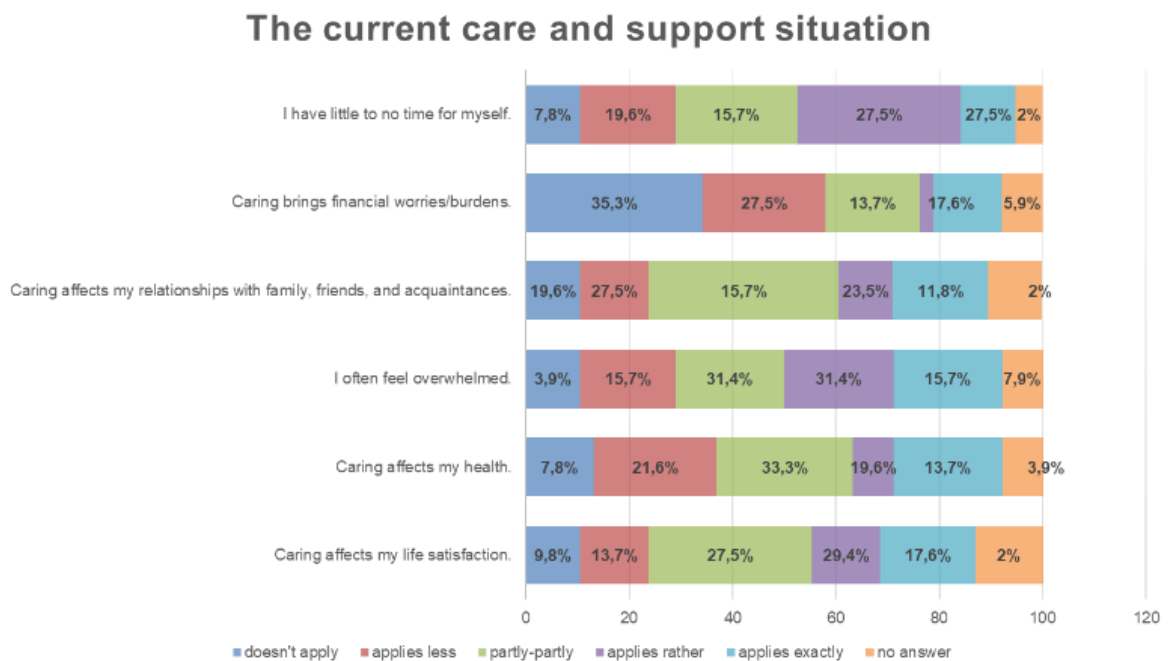


Figure 1: The current care and support Situation
(Questionnaire 1 (n=38) Evaluation Mobile Dementia Coaching)

Nearly all participants (95%) rated the Mobile Dementia Coaching service as very helpful, and 100% said they would recommend the service to others. The coaching sessions helped participants gain a better understanding of dementia and their role as a caregiver, which was seen as a significant benefit (Figure 2).

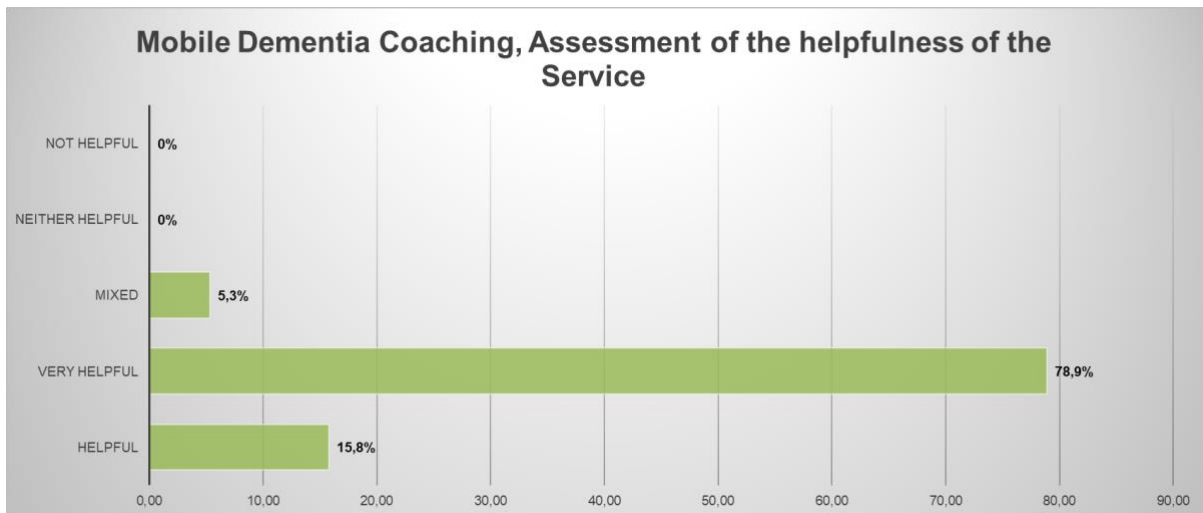


Figure 2: Mobile Dementia Coaching, helpfulness of the Service (Questionnaire 2 (n=19) Evaluation Mobile Dementia Coaching)

The second questionnaire, completed by 19 individuals who had made use of the Mobile Dementia Coaching service for a second time, provided additional insights: Participants reported that the coaching helped them better cope with the challenges of caregiving, with 89% indicating it had a positive impact on their ability to manage the care situation. Nearly three-quarters (74%) of participants said the coaching had reduced their overall burden and stress as a caregiver, highlighting the program's effectiveness in providing relief. The coaching also boosted participants' confidence in their caregiving role, with 84% reporting increased self-assurance in managing the demands of caring for a loved one with dementia (Figure 3).

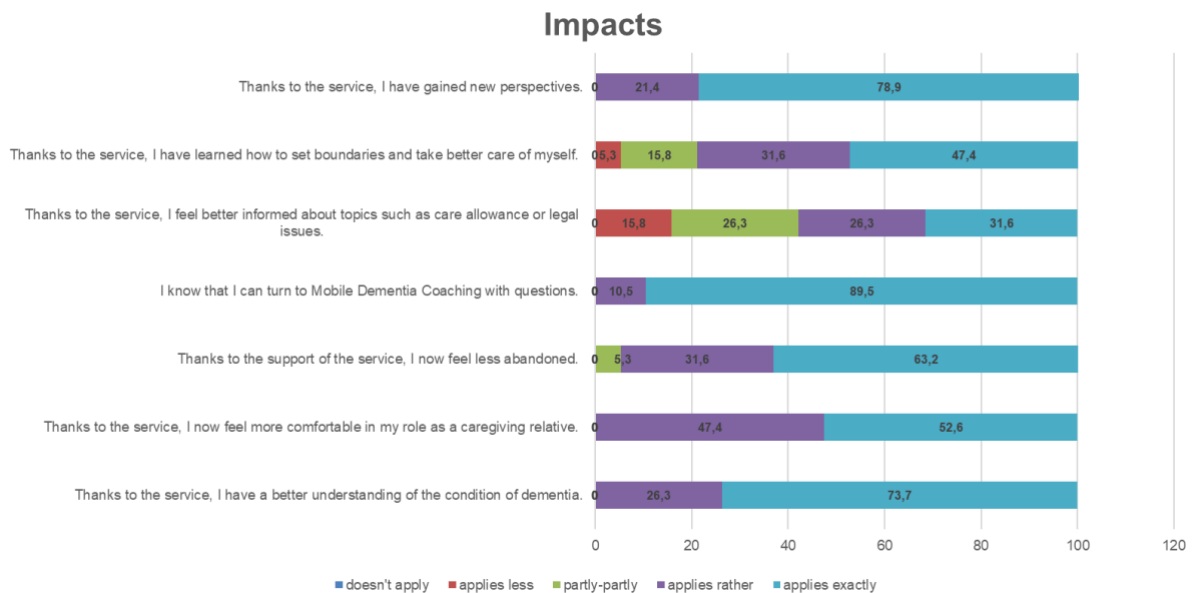


Figure 3: Impacts (Questionnaire 2 (n=19) Evaluation Mobile Dementia Coaching)

Interviews with three caregiving relatives revealed the significant burden and responsibilities they faced in caring for parents with long-term dementia, with varying levels of strain reported. Participants appreciated the diagnostic tests and psychological discussions provided through the Mobile Dementia Coaching, which they found to be highly valuable in

understanding the disease and their role as a caregiver. Caregivers highlighted the importance of the coaching's flexible and outreach-oriented nature, which made the support more accessible and tailored to their individual needs. While caregivers were willing to pay for the coaching service, they expressed concerns about the lack of financial support from the government for their caregiving responsibilities, and the need for increased visibility of the Mobile Dementia Coaching intervention.

Discussion

The study findings confirm the significant burden and stress experienced by family caregivers of individuals with dementia, underscoring the critical need for support services. The Mobile Dementia Coaching program was highly effective in improving caregivers' knowledge and understanding of dementia and their caregiving role. Caregivers expressed a high level of satisfaction with the mobile coaching service, praising its accessibility, flexibility, and the valuable information and relief it provided. The mixed-methods approach used in the evaluation was beneficial, and the researchers recommend continuing the program with long-term follow-up to measure its sustained impact.

Conclusion

The evaluation of the Mobile Dementia Coaching intervention has demonstrated its effectiveness in providing relief, knowledge, and health risk prevention for family caregivers of individuals with dementia. The positive feedback from participants, particularly regarding the program's accessibility and the valuable information and support it offered, highlights the importance of such outreach-oriented services. Based on the findings, the researchers recommend that the intervention should be continued to offer, with ongoing evaluation to measure its long-term impacts on caregiver well-being and the sustainability of the support provided. To reach more caregivers in need, the researchers suggest increasing the visibility and promotion of the intervention, particularly in light of the financial concerns expressed by participants regarding the lack of governmental support. Additionally, from a scientific point of view it would be relevant to explore the opportunities to expand the intervention's services and resources to further address the diverse needs and challenges faced by family caregivers of individuals with dementia.

References

- Diakonie. (2022, 16. September). Mobile Angebote für Menschen mit Demenz und ihre Angehörigen. <https://www.diakonie.at/unsere-angebote-und-einrichtungen/mobile-angebote-fuer-menschen-mit-demenz-und-ihre-angehoerigen>
- Helfferrich, C. (2011). Die Qualität qualitativer Daten: Manual für die Durchführung qualitativer Interviews (4. Aufl.). VS Verlag für Sozialwissenschaften.
- Mayring, P. (2002). Einführung in die qualitative Sozialforschung: Eine Anleitung zu qualitativem Denken (5. Aufl.). Beltz.
- Mayring, P. (2015). Qualitative Inhaltsanalyse: Grundlagen und Techniken (12. Aufl.). Beltz.
- Mosquera, I., Vergara, I., Larrañaga, I., Machón, M., Del Rio, M. & Calderón, C. (2016). Measuring the impact of informal elderly caregiving: a systematic review of tools. *Quality of Life Research*, 25(5), 1059-1092. <https://doi.org/10.1007/s11136-015-1159-4>
- Nagl-Cupal, M., Kolland, F., Zartler, U., Mayer, H., Bittner, M., Koller, M., Parisot, V., Stöhr, D. & Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz. (Hrsg.). (2018). Angehörigenpflege in Österreich. Einsicht in die Situation pflegender Angehöriger und in die Entwicklung informeller Pflegenetzwerke. Universität Wien. <https://broschuerenservice.sozialministerium.at/Home/Download?publicationId=664>
- Schacke, C. & Zank, S. (2009). Das Berliner Inventar zur Angehörigenbelastung – Demenz (BIZA-D). Manual für die Praxisversion (BIZA-D-PV). ZPE-Zeitschriftenreihe, 23. <https://www.hf.uni-koeln.de/data/gerontologie/File/BIZA-D-PV%20mit%209%20Items.pdf>

Contact email: c.pichler@fh-kaernten.at