**Universität Bremen**

**Fachbereich 11: Human- und Gesundheitswissenschaften**

# Development and replication of a typology of informal dementia care dyads to guide the design of tailored support for informal caregivers

An exploratory study based on cross-sectional analyses of dementia care network users in Germany and the Netherlands and international evidence

**Dissertation**

Zur Erlangung des Grades Doktor Public Health (Dr. PH)

vorgelegt von

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Kolloquium: 12. Juni 2024 in Bremen

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# Danksagung

Mein herzlicher Dank richtet sich an all diejenigen Menschen, die mich auf dem Weg der Erarbeitung dieser Dissertation begleitet haben.

Meiner Betreuerin Prof. Dr. Karin Wolf-Ostermann danke ich für das Vertrauen und den gegebenen Freiraum in der Durchführung meiner wissenschaftlichen Arbeit sowie der Unterstützung zu jeder Zeit im Entstehungsprozess. Prof. Dr. Benjamin Schüz und Prof. Dr. Karin Bammann danke ich darüber hinaus für die wissenschaftliche Begutachtung dieser Arbeit.

Prof. Dr. Birte Berger-Höger und Prof. Dr. Wolf Rogowski danke ich dafür, dass sie sich als Prüferin bzw. Prüfer für das Kolloquium zur Verfügung gestellt haben.

Prof. Dr. Karin Wolf-Ostermann und Prof. Liane Schirra-Weirich danke ich für die Unterstützung und Anregungen und dafür, dass sie meine Art und Weise wissenschaftlich zu denken und forschungspraktisch zu arbeiten, in meinen ersten Berufsjahren nachhaltig geprägt haben.

Mein Dank richtet sich auch an Prof. Dr. Werner Brannath, Prof. Dr. Hein van Hout, Dr. Farhad Arzideh, die durch ihre hilfreiche Beratung, Rückmeldungen und Beiträge zum Gelingen meiner wissenschaftlichen Arbeit beigetragen haben. Nachdrücklich danken möchte ich an dieser Stelle AP Dr. Niels Janssen für die vielen Stunden des Online-Gesprächs und der Diskussionen rund um die dritte Teilstudie dieser Thesis. Unsere Gespräche haben mich immer wieder „auf Spur gebracht“ und motiviert.

Dem Team des Projekts „PfADe“ sowie auch allen weiteren Ko-Autorinnen und Ko-Autoren meiner Einzelarbeiten danke ich besonders für die gute Zusammenarbeit.

Mein Dank richtet sich zudem an alle meine Kolleginnen und Kollegen von der Universität Bremen, insbesondere der Abteilung Pflegewissenschaftliche Versorgungsforschung des Instituts für Public Health und Pflegeforschung, die mich in meiner wissenschaftlichen Arbeit stets motiviert haben. Auch danke ich meinen Freundinnen und Freunden, meiner Kölner Bürogemeinschaft und meiner Familie dafür, dass sie mit viel Geduld immer wieder meinen Dissertationsgeschichten zugehört haben.

Köln, Januar 2024

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## Abbreviations

ADL: Activities of Daily Living

BIC: Bayesian Information Criterion

BIZA-D: Berlin Inventory of Caregivers' Burden with Dementia Patients

CINAHL: Cumulative Index to Nursing and Allied Health Literature

CMAI: Cohen-Mansfield Agitation Inventory

CBT: Cognitive Behavioural Therapy

COMPAS: Collaborative dementia care for patients and caregivers study

DCN: Dementia Care Network

DemNet-D: Evaluation study of dementia networks in Germany [Multizentrische, interdisziplinäre Evaluationsstudie von Demenznetzwerken in Deutschland]

EQ VAS: European Quality of Life Visual Analogue Scale

FAST: Functional Assessment Staging Tool

FINGER: Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability

FMM: Finite Mixture Models

GBD: Global Burden of Diseases, Injuries, and Risk Factors Study

GISD: Regional Socioeconomic Deprivation

HIC: High Income Countries

IADL: Instrumental Activities of Daily Living

LCA: Latent Class Analysis

LC: Latent Class

LRT: Likelihood Ratio Test

LTA: Latent Transition Analysis

LTC: Long Term Care

MAR: Missing At Random

MMSE: Mini-Mental-Status-Examination

BCH: Bolck-Croon-Hagenaars

NPI: Neuropsychiatric Inventory

OECD: Organisation for Economic Cooperation and Development

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

PROSPERO: International Prospective Register of Systematic Reviews

QoL: Quality of Life

QoL-AD: Quality of Life in Alzheimer Disease

RCT: Randomized Controlled Trial

RSES: Regional Socio-Economic Status

RUD: Resource Utilization in Dementia

SoCA: Stability of Care Arrangements

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

USA: United States of America

WHO: World Health Organization

## Zusammenfassung

Die Anzahl von Menschen mit Demenz nimmt weiterhin zu, und viele Menschen mit Demenz haben den Wunsch, so lange wie möglich zu Hause zu leben. Im Rahmen dieser häuslichen Versorgungsarrangements spielen informell Pflegende häufig eine zentrale Rolle. Sie sind dadurch jedoch oft erheblich belastet und es zeigen sich nachweisbare Auswirkungen auf ihre gesundheitliche Verfassung. Zwar betonen zahlreiche Studien die entscheidende Rolle von psychosozialen Unterstützungsmaßnahmen für informell Pflegende in häuslichen Demenzpflege-Dyaden. Dennoch herrscht weitgehender Konsens darüber, dass bestehende Unterstützungsstrukturen bisher nicht ausreichend auf die unterschiedlichen Bedürfnisse von informell Pflegenden in verschiedenen dyadischen Versorgungskonstellationen zugeschnitten sind. Um Unterstützungsstrukturen akzeptabler und effektiver zu gestalten, wäre es demnach von Bedeutung, sie an spezifische dyadische Konstellationen in häuslichen Versorgungsarrangements bei Demenz anzupassen.

Übergeordnetes Ziel der vorliegenden Arbeit ist die Identifizierung typischer dyadischer Beziehungskonstellationen in der häuslichen Demenzversorgung sowie die Analyse von Gemeinsamkeiten und Unterschieden hinsichtlich psychosozialer Outcomes mit besonderem Fokus auf informell Pflegende als zentrale Akteure in Demenzpflege-Dyaden. Dazu wurden drei Einzelbeiträge veröffentlicht, die 1. sowohl die Wirksamkeit als auch die Subgruppenorientierung von psychosozialen Interventionen zur Förderung der psychischen Gesundheit informell Pflegender bei Demenz zusammenfassen, 2. eine Subgruppentypologie und damit verbundene psychosoziale Gesundheitsoutcomes innerhalb von Demenzpflege-Dyaden mittels einer latenten Klassenanalyse (LCA) auf Basis von Daten der deutschen DemNet-D-Studie darstellen und 3. diese Subgruppentypologie im Rahmen einer Replikationsstudie mit Daten der niederländischen COMPAS-Studie testen und überprüfen. Ferner werden die Ergebnisse im Hinblick auf die zugrunde liegenden Konzepte der psychosozialen Gesundheit, der dyadischen Perspektive und der Subgruppenorientierung reflektiert.

Es gibt weiterhin einen Mangel an Studien, die gezielte Interventionen für spezifische Untergruppen von informellen Pflegepersonen in häuslichen Demenzpflege-Dyaden untersuchen. Dieses Ergebnis zeigt sich noch deutlicher, wenn man nach mehrdimensionalen Ansätzen zur Identifizierung von Untergruppen sucht. Dies kann ein Grund dafür sein, warum bisherige Interventionen nur eingeschränkt wirksam waren. Zusätzlich zeigen die Analysen, dass eine modellbasierte multidimensionale Identifizierung typischer dyadischer Subgruppen in der häuslichen Demenzversorgung möglich ist und Ansatzpunkte für die Bereitstellung

maßgeschneiderter Gesundheitsversorgung bietet. Allerdings waren die Ergebnisse der durchgeführten Replikation in einigen Aspekten begrenzt und daher nur teilweise erfolgreich. Zukünftige Forschungsprojekte sollten sich mit dieser Herausforderung befassen und weitere Schritte zur Harmonisierung von Kernindikatoren über verschiedene Studien und Länder hinweg unternehmen.

Insgesamt zeigt die vorliegende Arbeit auf, wie typische Subgruppen von Demenzpflege-Dyaden in häuslichen Versorgungsarrangements unter Verwendung von quantitativen Daten in einem modellbasierten und multidimensionalen Ansatz identifiziert werden können. Sie weist auch auf die Herausforderungen bei quantitativen Projekten hin, wie die Schwierigkeit, erste Ergebnisse mit strukturell ähnlichen, aber verschiedenen Populationen zu replizieren. Diese Arbeit könnte einen wertvollen Beitrag zu weiteren Debatten darüber leisten, wie die Wirksamkeit psychosozialer Interventionen für informelle Pflegepersonen mit Demenz durch maßgeschneiderte Unterstützung verbessert werden kann.

## Abstract

The number of people living with dementia continues to increase, and many of them wish to live at home for as long as possible. Informal caregivers are at the centre of the home-based care arrangements. However, they're usually under a lot of pressure, and it has been proven that this impacts their health negatively. Many studies highlight the importance of providing psychosocial support services to caregivers in dementia care dyads. However, it is widely agreed that current support structures are still not sufficiently tailored to the different needs of informal carers in various dyadic constellations. To improve the effectiveness of support for informal caregivers, it is crucial to better tailor them to specific dyadic constellations in home-based dementia care.

The overall aim is the identification of typical dyadic relationship constellations in home-based dementia care settings. A further goal is the analysis of similarities and differences regarding relevant health-care related psychosocial outcomes, with a special focus on informal caregivers as individuals in dementia care dyads. Therefore, three single papers were published, that 1. synthesises both effectiveness and subgroup-orientation of psychosocial interventions promoting mental health of informal caregivers, 2. presents a subgroup-typology and related health care outcomes of informal caregivers within dementia care dyads, using a latent class analysis (LCA) based on data from the German DemNet-D study, and 3. tests and controls this subgroup-typology within a LCA replication study, using data from the Dutch COMPAS study. Furthermore, the results are reflected against the underlying concepts of psychosocial health, dyadic perspective and subgroup-orientation.

The results indicate that there is still a shortage of studies concentrating on targeting interventions for specific subgroups of informal caregivers in home-based dementia care dyads. The situation is even more evident when searching for multidimensional approaches to identify subgroups. This could be a reason why previous interventions have only been modestly effective. Furthermore, the analyses were able to show that a model-based multidimensional identification of typical dyadic subgroups in home-based dementia care is feasible and provides entry points for providing tailored health support. Nevertheless, replication of those initial results was limited in some aspects and only partially successful. However, future research projects should address this issue and take further steps towards the harmonisation of core indicator sets across studies and countries.

Overall, this thesis contributes to the understanding of how to identify relevant subgroups of dementia care dyads in home-based setting, using quantitative data in a model-based and multidimensional approach. It also identifies challenges for quantitative projects, such as the

difficulty of replicating initial findings with structurally similar but different populations. This thesis might be a valuable input for further debates on how to improve the effectiveness of psychosocial interventions for informal dementia caregivers through tailored support.

# 1. Introduction

This section provides background information and fundamental ideas related to this overall dissertation. Dementia is described including its basic symptoms, and key facts about its epidemiological development are outlined. The subsequent discussion covers what we know about informal dementia caregiving, before examining dyadic constellations. Finally, the structure of this thesis is described before an overview of the individual papers included in this cumulative thesis is provided.

## 1.1. Dementia: concept, epidemiology and informal care

The dementia syndrome

The term "dementia" describes a clinical syndrome, which is typically associated with difficulties in memory, language and verbal fluency, visuospatial function affecting perception and orientation, problem-solving and other abilities related to thinking (Alzheimer's Association 2022). Psychological symptoms often include depression, psychotic hallucinations and delusions, apathy, and anxiety. Social withdrawal is the most common symptom related to social relations (ibid.). There are different types of dementia, depending on the underlying cause of the disease. Approximately 60 % of diagnosed dementias in Germany are Alzheimer's dementias. Another 20 % are vascular dementias. Lewy body dementia accounts for 15 % and frontotemporal dementia for 5 %. In general, dementias can manifest at any age, but the risk rises considerably with increasing age. Dementia is more common in women than in men (ibid.).

In epidemiology, risk factors define an increased likelihood of developing a particular disease. For dementia, several risk factors are known over the life course. Beside genetic predispositions, in very early life, factors like prenatal environments, low childhood socioeconomic status and air pollution play a role. In the later stages of early life, low education, personality, alcohol misuse and passive jobs are important. In midlife, an unhealthy diet, smoking, head trauma and obesity come in, together with hypertension, physical inactivity, job strain and diabetes in the further course of the middle part of life. In late life, the relevant risk factors for dementia are sensory deficits, cardiovascular and cerebrovascular disorders as well as depression, little mental stimulation and social isolation (Fratiglioni et al., 2020; Livingston et al., 2020). Dementias usually have a progressive course that can be classified into consecutive stages on a disease continuum. This progression starts with unnoticeable brain changes, which may lead to problems later in the process with cognitive abilities and possibly physical disability. The course of dementia can span over several years. Studies indicate that persons live between 4 and 8 years after a diagnosis (Alzheimer's Association, 2022). The remaining life expectancy of individuals living with dementia indicates that the heterogeneity of predictors and markers of cognitive decline as well as dementia trajectories. This heterogeneity is attributed to individual differences in the accumulation and interaction of various risk and protective factors over the life course, as mentioned above (Livingston et al., 2020). Since there are no effective pharmaceutical or medical therapies for the prevention or cure of dementia in sight, psychosocial intervention approaches, such as cognition training, exercise programs, music therapy, group therapy or the promotion of social interactions, play a particularly important role (Moniz-Cook et al., 2008; Shah et al., 2016; Vernooij-Dassen et al., 2019; Livingston et al., 2020).

The challenges that dementia brings for care and nursing differ in some aspects from the care and nursing of people with other care needs (Ory et al., 1999, Alzheimer's Association, 2022; Parker et al., 2022). Usually, as a common consequence of dementia, memory loss and cognitive impairment occur. This means that people living with dementia often experience difficulties in retaining information and remembering everyday things. They may also struggle with attention, logical thinking, and problem-solving (Cipriani et al., 2020, Gale et al., 2018). Another difficulty in caring and nursing of people with dementia is the loss of language abilities. As dementia progresses, individuals may have difficulties expressing themselves verbally or understanding language. Communication becomes a challenge (ibid.). In addition, there are often problems with mobility and self-care. With the progression of dementia, mobility may be impaired, and the ability to perform self-care tasks may decline (ibid.). Furthermore, changes in behaviour such as restlessness, aggression, anxiety, or delusions frequently occur (Gitlin et al., 2015). Last but not least, dementia can result in social isolation as individuals have difficulties maintaining social interactions and may feel uncomfortable in social situations (Vernooij-Dassen et al., 2022). Vice versa, it is not unusual for people with dementia to experience social stigmatization, which can cause them to withdraw from social life as they feel excluded (ibid.).

### Epidemiology of dementia

Dementia has been recognized recently as a global public health and social care challenge on various societal levels ranging from governments, communities, families to individuals (Shah et al., 2016; Livingston et al., 2020; World Health Organization, 2021). As age-associated neurodegenerative diseases, the increasing societal relevance of dementia has to be considered in the context of demographic ageing processes. Looking back at the past 30 years, there has been a global increase in the total number of individuals living with dementia, mainly driven by increasing life expectancy and an accompanying increase in the number of elderly individuals over 80 and 90 years of age, when dementia is most prevalent (GBD, 2019). Thus, the prevalence increases significantly with age: In Europe, the prevalence rate is 1.85 % for individuals aged 65 to 69, but it rises to more than 36 % for individuals aged over 90 years of age (van der Flier/Scheltens, 2005; Bickel, 2022). According to estimates by the World Health Organization (WHO), there were approximately 55.2 million people living with dementia worldwide in 2019 (WHO, 2021). It is expected that the total number of individuals living with dementia will continue to increase globally, reaching 152.8 million in 2050 (GBD, 2019). Europe has the second-highest number of people with dementia, 14.1 million, second only to the WHO Western Pacific Region. Recent studies suggest that the incidence in so-called high-income countries (HIC), e.g., USA, France, Great Britain, has been dropping over the last three decades (GBD, 2019). This, it is suggested, may be due mainly to improved protective factors like education, nutrition, health care, and lifestyle indicators (Livingston et al., 2020). However, other studies consider this rather as a kind of “long-term snapshot,” expecting that risk factors such as diabetes, smoking, physical inactivity or low social interactions could soon lead to an increase in the incidence of dementia in HIC (ibid.). A glance at economic cost models for dementia illustrates the pressure on health systems: The World Health Organization (WHO) Global Status Report on the Public Health Response to Dementia estimates that the global cost of dementia will be US$ 1.3 trillion in 2019, a figure that is expected to rise to about US$ 2.8 trillion by 2030 (WHO, 2021). Most people with dementia live at home (Alzheimer Europe, 2014; WHO, 2021). They prefer to stay in their familiar places as long as they can as it provides a sense of continuity, autonomy, and security (van der Roest et al., 2009; von Kutzleben et al., 2016). Informal caregivers – mainly family members, but also friends – provide the majority of dementia care, accounting for an estimated 40 % of the total cost of dementia worldwide (OECD, 2018).

### Informal dementia caregiving

Informal caregivers provide care in many ways, including preventive care, supervision, and reciprocal care. Informal care is an important pillar of many long-term care (LTC) systems internationally. At the political level, informal care is considered as a cost-effective way to avoid institutionalization and help elderly people to age in place (Wiles et al., 2012; European Commission, 2018). Modelling suggests that this unpaid work is predominantly provided by women, who contribute 71 % of the global hours of informal dementia care (Wimo et al., 2018).

The majority of dementia care is provided in the home, with variations across regions of the world. For example, in so-called high-income countries such as the USA, Japan, Australia, or Germany, 69 % of dementia care is provided in the home, whereas in low-income countries, this figure is much higher (93-98 %). Globally, the estimated proportion of people with dementia receiving care at home is 84 % (Wimo et al., 2018). There is no common definition of what an informal caregiver is. For the purpose of the present study, we built on the broad definition given by Dreyer et al. (2022). Following this definition, informal carers are people in the person's immediate social environment who support the person with dementia without being paid for this. Studies have shown that besides a primary informal caregiver, other people (e.g., family members, neighbours, friends, volunteers) are likely to be involved in the informal care network surrounding a person with dementia. However, much of the care work that occurs is provided by an individual person (Schulz/Martire, 2004; Wimo et al., 2018). With this individual person, the informal caregiver, the person living with dementia forms an intensive reciprocal relationship. This intensive liaison is referred to in scientific discourse as a dyadic relationship.

The dyadic relationship between individuals living with dementia and their informal caregivers has gained considerable attention recently. Given the mutual influence exerted by both parties, it appears rational and effective to devise psychosocial support in a dyadic fashion, rather than focusing solely on each individual (Smits et al., 2007; Braun et al., 2009; van’t Leven et al., 2013; Rausch et al., 2017). Moreover, recent research indicates that dyadic constellations in home-based care arrangements have a heterogeneous nature and reveal disparities in terms of socio-demographic, relational, and geographic features of the dyad. Such differences between certain dyadic subgroups may have a considerable impact on relevant clinical outcomes for both individuals involved, differences that should be addressed when planning effective support services (Pinquart/Sörensen, 2011; Wang et al., 2011; Robinson et al., 2014; Karrer, 2016; Koyama et al., 2017; Laporte-Uribe et al., 2017; Abrahams et al., 2018; Akarsu et al., 2019).

Due to the burden associated with care work, many informal caregivers in dementia care dyads are significantly at risk for biopsychosocial health disadvantages (Ekwall et al., 2005; Sörensen/Conwell, 2011; Karg et al., 2018). In particular, psychological distress plays a central role (Pinquart/Sörensen, 2006; Brodaty/Donkin, 2009; Kim et al., 2008; Koyama et al., 2017). However, the support services that have been systematically tested to reduce stress and strain and promote the mental health of informal caregivers too often provide only short-term relief and have little effect (Brodaty, 2003; Mantovan, 2010; Martin-Carrasco et al., 2014;

Wiegelmann et al., 2021). Results from reviews suggest that a lack of tailoring of support services to specific care contexts may be one of the reasons for this situation, and that improved tailoring may lead to greater effectiveness (Smits et al., 2007; van Mierlo et al., 2012). This dissertation, therefore, aims to contribute to the discussion on improving the tailoring of psychosocial support for informal carers of individuals living with dementia in home-based care arrangements.

## 1.2. Cumulative dissertation outline

The thesis is structured as a cumulative dissertation with three consecutive single studies. The project is based on analyses of multiple datasets. The common objective of the original research projects was to analyse and improve the care situations of people with dementia and their family caregivers. The data basis of the 1st article was developed in the context of the project "Preventive care structures for informal caregivers of persons living with dementia" (Wolf-Ostermann et al., 2020). The basis of the 2nd article is data of the multicentre, interdisciplinary evaluation study of dementia networks in Germany (DemNet-D), conducted in 2012-2015 (Wolf-Ostermann et al., 2017; Thyrian et al., 2018). The 3rd article uses primary data from the Dutch research project COMPAS (MacNeil Vroomen et al., 2012). The following Table 1 presents the individual publications, as well as their underlying research questions and research methodology.

*Table 1 Publications - Research questions and methods*

| **Publication** | **Research questions** | **Methods** |
|---|---|---|
| **"Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review"** | What interventions have been used to improve the mental health of informal caregivers of people with dementia?<br>What effects on mental health are reported?<br>To which specific subgroups of informal caregivers do the intervention programs refer?<br>What effects are reported for interventions targeting a specific subgroup? | Systematic literature review with narrative synthesis |

| | | |
|---|---|---|
| **“Dyadic subgroups in dementia caregiving –**<br>**A latent class analysis of home-based care arrangements”** | Which typical dyad subgroups can be identified using a model-based LCA?<br>How can these dyad subgroups be described in a typology?<br>What are the differences in health and health care outcomes between the dyad types? | Secondary data analysis (cross-sectional); latent class analysis (LCA, Latent Class Analysis; Step3 approach |
| **“Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads: a latent class replication study”** | Is the typology developed in the first analysis replicated in a second data set?<br>What differences and similarities emerge in the comparison of the latent class analyses?<br>What are the scientific and practical implications? | Secondary data analysis (cross-sectional); latent class analysis (LCA, Latent Class Analysis; Step3 approach; qualitative comparison |

Chapter 1 provided an introduction to the thesis. The concept of dementia was presented, as well as key research findings regarding the epidemiology of dementia and informal dementia care. In Chapter 2, the conceptual and empirical positioning of this work is highlighted, focusing on psychosocial health of informal dementia caregivers and the dyadic perspective. It explores how heterogeneity can be recognised, and how this can be implemented conceptually, methodologically, and statistically. Moreover, this section summarises the significance of the thesis and identifies the research gaps it addresses. Chapter 3 presents the research questions as well as the overarching aim and objectives of this dissertation. Chapter 4 is devoted to the methodology used in the three individual publications. Following this, Chapter 5 presents the research context of each paper in detail, including main findings, points of discussion, and a summary of key findings. The discussion of the findings is the main part of Chapter 6. The research findings are explored and discussed within the conceptual and empirical positioning of the thesis. Subsequently, the methodical approach is discussed as well. Furthermore, this section highlights both the strengths and limitations of the thesis and presents the knowledge that has been gained. Chapter 7 explores the implications for research, practice, and policy, drawing upon the findings presented throughout the thesis. Chapter 8 presents an overall conclusion of the thesis. Additionally, the bibliography and appendices offer supplementary information and support for the topics addressed in the thesis.

### 1.3. List of first-authorship publication comprised in this dissertation

This thesis is based on a systematic literature review and two latent class analyses, of which the second LCA is a replication of the first LCA. This cumulative dissertation consists of three individual papers (publications as first author). All papers have been published in peer-reviewed, international journals.

***Publication 1***

The first publication in this dissertation is a systematic literature review with a narrative synthesis.

Citation: Wiegelmann H, Speller S, Verhaert LM, Schirra-Weirich L, Wolf-Ostermann K. *Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia - a systematic literature review*. BMC Geriatr. 2021;21(1):94. Published 2021 Feb 1. doi:10.1186/s12877-021-02020-4

Author Contribution

HW designed the study in conjunction with KWO. HW performed literature search, data retrieval, selection process, and charting of the data in cooperation with SS. HW analysed the data, interpreted the results, and took the lead in writing the manuscript. KWO aided in analysing and interpreting the results and worked on the manuscript. KWO, LSW, and LMV critically reviewed the drafts and the final manuscript. HW led the authors' responses to the reviewers' feedback, collated the response, and redrafted the final manuscript, which was advised and supported by KWO. All authors approved the submitted manuscript.

***Publication 2***

The second publication in this thesis is a latent class analysis using cross-sectional data collected in the German DemNet-D study.

Citation: Wiegelmann H, Wolf-Ostermann K, Brannath W, et al., *Sociodemographic aspects and health care-related outcomes: a latent class analysis of informal dementia care dyads*. BMC Health Serv Res. 2021;21(1):727. Published 2021 Jul 23. doi:10.1186/s12913-021-06708-6

Author Contribution

HW designed the study in collaboration with KWO and FA. WB and FA performed the statistical analysis in close consultation with HW. HW analysed the data and interpreted the results in collaboration with KWO and FA. HW took the lead in writing the manuscript. KWO aided in analysing and interpreting the results and worked on the manuscript. JD and RT have read and commented on the full document. HW led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript, which was advised and supported by KWO. The authors read and approved the final manuscript.

***Publication 3***

The third publication in this thesis is a latent class analysis aiming to replicate the second sub-study. This study uses data collected in the Dutch COMPAS study.

Citation: Wiegelmann H, Wolf-Ostermann K, Janssen N, van Hout H, Vroomen JLM, Arzideh F. *Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads: a latent class replication study.* BMC Health Serv Res. 2023;23(1):482. Published 2023 May 12. doi:10.1186/s12913-023-09505-5

Author Contribution

HW conceived and planned the study in consultation with KWO. HW conducted the data preparation, assisted by HEvdH who made the data available. HW performed the statistical calculations in consultation with FA. HW analysed the results in collaboration with KWO and NJ. HW took the lead in writing the manuscripts. KWO and NJ aided in analysing and interpreting the results and worked on the manuscript. HEvdH and JMV read and commented on the full document. HW led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript. The author(s) read and approved the final manuscript.

### 1.4. Publications and research outputs related to the work of this dissertation

Oral presentations:

- **Wiegelmann H**, Schirra-Weirich L, Verhaert LM, Brannath W, Arzideh F, Wolf-Ostermann K (2019, September) Gesundheitsförderung für pflegende Angehörige von Menschen mit Demenz: Ergebnisse eines systematischen Reviews. Gemeinsame Fachtagung der Sektion III: Sozial- und verhaltenswissenschaftliche Gerontologie und der Sektion IV: Soziale Gerontologie und Altenarbeit der Deutschen Gesellschaft für Gerontologie und Geriatrie (DGGG), 19.-20. September 2019 in Berlin, Deutschland.
- Wolf-Ostermann K, **Wiegelmann H**, Verhaert LM, Schirra-Weirich L, Arzideh F, Brannath W (2019, October). Are there typical dyads of persons with dementia and their informal caregivers and what do we know about differences in observed quality of life and social participation? Results from the German PfADe-Study. 29th Alzheimer Europe Conference, 23-25th October 2019, The Hague, Netherlands.

- **Wiegelmann H**, Verhaert LM, Schirra-Weirich L, Arzideh F, Brannath W, Wolf - Ostermann K (2019, May). Do Typical Patterns of Persons with Dementia and Their Informal Caregivers Exist? Results of a Latent Class Analysis of Home-Based Dyadic Care Arrangements. 9th International Association of Gerontology and Geriatrics European Region Congress 2019 (IAGG-ER). 23-25 May 2019 in Gothenburg, Sweden.
- Wolf-Ostermann K, **Wiegelmann H** (2019, May). Präventive Versorgungsstrukturen für versorgende Angehörige von Menschen mit Demenz – Ergebnisse des Projekts PfADe. 6. BZgA-Bundeskonferenz "Gesund und aktiv älter werden", 16.05.2019 in Berlin, Deutschland.
- **Wiegelmann H**, Wolf-Ostermann K (2019, May). Präventive Maßnahmen für versorgende Angehörige von Menschen mit Demenz. (mit H. Wiegelmann) Bremer Pflegekongress 10.05.2019 in Bremen, Deutschland.

Poster presentations:

- **Wiegelmann H**, Schirra-Weirich L, Verhaert L, Brannath W, Arzideh F, Wolf-Ostermann K (2018, October). The PfADe-study: Health care support for dementia caregiver dyads – How does social inequality matter? 28th Alzheimer Europe Conference, 29-31 October 2018 in Barcelona, Spain.

Scientific reports and papers:

- Wolf-Osterman K, **Wiegelmann H**, Schirra-Weirich L, Verhaert LM, Brannath W, Arzideh F (2020). Präventive Versorgungsstrukturen für versorgende Angehörige von Menschen mit Demenz (PfADe). Modellprojekt zur Weiterentwicklung der Pflegeversicherung gemäß §8 Absatz 3 SGB XI. https://www.gkv-spitzenverband.de/media/dokumente/pflegeversicherung/forschung/projekte_unterseiten/20201010_PfADe_Endbericht_homepage.pdf [22.10.2023]
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## 2. Conceptual and empirical positioning

This chapter provides a conceptual and empirical positioning of this dissertation. It introduces the main terms and concepts and presents the current state of research in relevant areas. First, the concept of ‘psychosocial health’ is presented and related to informal caregivers in home-based dementia care. Second, the following section addresses the concept of ‘the dyad’ and explains how this concept is made useful for the present study. Thirdly, the concept of ‘tailoring’ is discussed, which is a relevant approach to the issue of heterogeneity of target groups, both in general and, in our case, for the group of informal caregivers in home-based dementia care dyads.

### 2.1. Psychosocial health of informal dementia caregivers

In 1948, the WHO defined health as a “state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO 2020). With its positive and multidimensional approach, this definition had a profound influence on expanding the general understanding of health and policy beyond the traditional scope of the medical field, moving towards a biopsychosocial model of health. In the subsequent decades, these developments also laid the foundation for discussions on more person-centred and relationship-centred care in various practice settings and among diverse health professions (Peter et al., 2022). The concept “psychosocial” can be described as an umbrella term. It has been used very varied within health research and often lacks a clear definition or conceptual underpinning. Following the given by Molineux (2017), the term psychosocial refers to the influence of social factors on a person’s mental health or behaviour and to the mutual influences of behavioural and social factors. Martikainen and colleagues (2002) place the term in an extended health framework covering a micro, meso and macro levels. Psychosocial is a meso concept addressing phenomena produced within meso-level social formations like the family, circle of friends, the firm, or the club (Martikainen et al., 2002). This helps to clarify and distinguish the otherwise somewhat ambiguous concept of “social” from macro-level social factors, also known as social determinants of health, such as income and wealth distribution, legal and welfare structures, or gender- or race-specific power structures (ibid.). “Psychosocial” refers to the interaction between psychological and social factors in a person's life and how these factors influence a person’s mental and emotional well-being (Peter et al., 2022). Psychosocial interventions are often also referred to as non-pharmacological interventions. This is equivalent to a negative definition, where something is explained by what it is not. Negative definitions are typically used when it is difficult to define a term positively, or when it is important to distinguish it from other terms. Non-pharmacological interventions (NPI) refer to interventions or treatments that do not involve the use of pharmaceutical drugs. Not all non-pharmacological interventions are psychosocial in nature. While non-pharmacological interventions can include psychosocial strategies, they are not limited to them. Non-pharmacological interventions can also include nutritional interventions, digital health interventions, or various other neuro and physical stimulation techniques that aim to improve health without the use of medications (Castellano-Tejedor 2022). In turn, psychosocial interventions aim to improve mental health, emotional well-being, overall quality of life (QoL), or social participation. They can include therapies like cognitive-behavioural therapy (CBT), counselling approaches, support groups, provision of information, communication training, teaching stress management techniques, and learning time management strategies and self-care practices (ibid.). In this thesis, the aspect of psychosocial health is considered, as all three sub-studies refer to the analysis of psychosocial health outcomes of informal dementia caregivers.

### Psychosocial health of informal caregivers of persons living with dementia

Informal caregivers—predominantly family members but also friends or neighbours — play a significant role in home-based dementia care. When models are used to calculate the costs of care per person with dementia, the value of this so-called informal care work done by family members amounts to slightly more than two-thirds of the total costs arising (von Kutzleben 2018). Women are more likely than men to take on the role of family caregivers. Although the proportion of male informal caregivers has increased over the past two decades, it is estimated that women account for about 70 % of unpaid dementia care work worldwide (Wimo et al., 2018). Informal caregivers mention various aspects as motivation for taking over care work at home in the context of dementia. These may be influenced, among other things, by traditional gender roles, dyadic relationship constellations, the housing situation, socioeconomic resources, or cultural influences. A relevant proportion of informal caregivers of individuals living with dementia (men 33 %; women 39 %) state that they had no choice but to take on this role. Other reasons include a desire to ensure and improve the well-being of the person in need of care or a sense of familial-generational obligation to return the care received as children. Additionally, relatives sometimes also see the assumption of care work as a biographical extension of existing caregiving roles within their relationship history (Erol et al., 2015).

As described above, dementia trajectories can extend over many years, with a transition process featuring some important turning points: the diagnosis of dementia, the realization of an increased need for formal support to sustain care at home, and the move of the person with dementia to a care home (Lethin et al., 2016). Thus, caring for a person with dementia is not a decision that concerns a short-term and foreseeable period of time. It involves the need to adjust to a dynamic care situation that will have a considerable impact on their lifestyle for years to come. Throughout the course, informal caregivers strive to keep the care situation stable and ensure that things are balanced (Köhler et al., 2022). While some caregivers find ways to create arrangements that remain stable for years, others might struggle with difficulties, fail to cope with critical situations, and initiate the transition to an institutional setting at an early stage (Dreyer et al., 2022).

The literature describes that informal caregiving typically includes multiple elements of a chronic stress experience. It challenges you physically and mentally for a long time. It is unpredictable and difficult to control, and it can cause more stress in other social areas of life, such as work, family, and friendship relations, and it requires high levels of sustained attention (Schulz/Sherwood, 2008). This frequently occurring stressful experience increases the likelihood of adverse health consequences, in psychological, physical, and social dimensions (Gilhooly et al., 2016). The following subsections summarise key research findings on negative social and psychological health effects of informal caregiving in dementia. However, the literature also points to positive effects, and a brief summary of the most important findings is presented as well.

### Negative effects of caregiving on the social health of informal dementia caregivers

Social health is a relatively new and unknown concept compared to the concept of psychological health. Therefore, a brief introduction. It was developed by Huber and colleagues based on a critique of too narrow an understanding of health. Social health was defined by them as the influence of social environmental aspects in finding a balance between one's capacities and health restrictions (Huber et al., 2011). The relational approach is at the very centre of the concept, with wellbeing defined based on two factors: firstly, the impact that an individual has on others within their social environment, and secondly, the impact that the social environment has on the individual in return (Vernooji-Dassen et al., 2022). Social health markers include, for instance, social contacts, social support, social participation, social leisure activities. Studies have shown that these markers positively influence physical, mental, and cognitive health of individuals (Berkman et al., 2000; Patterson/Veenstra 2010; Steptoe et al., 2013; Samtani et al., 2022, Mahalingam et al., 2023).

In general, informal caregiving increases the risk of social isolation and loneliness as it becomes more difficult for caregivers to find respite and, due to the care work, to maintain existing social contacts or establish new ones beyond the dyadic relationship (Rausch et al., 2017). The reasons frequently mentioned for the difficulties in keeping up social contacts are exhaustion and a lack of flexibility in terms of time or place (Schulz et al., 2016; Lee et al., 2021). However, studies have also shown that emotional closeness between, for example, a married couple or friends, may protect them from feeling lonely (Stokes, 2017; Victor et al., 2021). Social health and psychological health are interrelated in many ways. To mention just a few: For example, studies have proven that a lack of social relationships can have negative mental effects, e.g., regarding QoL (Berkman et al., 2000; Ekwall et al., 2005). Another example is the negative effect of social stigma on mental well-being (Rewerska-Juśko/Rejdak, 2020, van den Bossche/Schoenmakers, 2021). Conversely, mental health problems (e.g., depression, apathy) may lead people to have less interest in social relationships, resulting in social withdrawal (Nordtug et al., 2011; Zhang et al., 2021).

### Negative effects of caregiving on the psychological health of informal dementia caregivers

Dementia often causes a decline in cognitive abilities, which increases the person's need for assistance with important activities of daily living. Informal caregivers also encounter difficulties arising from behavioural changes—such as aggression, anxiety, or paranoia—that frequently accompany dementia. Due to these consequences, it is generally recognised that caring for a person with dementia is associated with increased stress experiences for informal carers (Cooper et al., 2007; Losada-Baltar 2016). Numerous studies indicate that mental health issues play a central role in the overall well-being of informal dementia caregivers (Pinquart/Sörensen 2006; Kim/Schulz 2008; Koyama et al., 2017). For example, depression and anxiety are at increased risk as a result of daily stress (Cooper et al., 2007). Additionally, caregivers experience increased burden and reduced QoL (Papastavrou et al., 2007; Karg et al., 2018). Furthermore, if the mental health of the informal caregiver declines, it is more likely that the individual with dementia will need to be institutionalised (Brodaty et al., 2003). This can adversely affect their QoL (Ekwall et al., 2005) and social involvement (Nay et al., 2015). Although institutionalisation may decrease the daily caregiving responsibilities for informal caregivers, it can also result in emotions of guilt, anger, anxiety, depression and financial difficulties (Brodaty/Donkin, 2009). Compared to caregivers of individuals with other illnesses, dementia caregivers experience worse mental health indicators such as distress, stress, burden, and subjective well-being (Sörensen/Conwell, 2011). This heightened burden is attributed to the fact that dementia caregivers spend more hours per week providing care and assisting with more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) (Karg et al., 2018; Brodaty/Donkin 2009). Furthermore, dementia can cause behavioural changes that may result in increased levels of mental stress and depression in caregivers (Ory et al., 1999). There is evidence of heterogeneity within the group of family caregivers regarding their susceptibility to mental health problems. Studies suggest that various factors, such as those listed below, can increase susceptibility: a) Sociodemographic factors such as being female, being in a spousal relationship, cohabiting, and having lower income or financial struggles; b) Factors related to the disease, including frontotemporal dementia, the duration of caregiving, an increase in neuropsychiatric symptoms, behavioural issues, and difficulty with basic activities. Caregiver characteristics, such as high neuroticism, high expressed emotion, less secure attachment style, low confidence in caregiving role, high role captivity, and emotion-based and confrontational coping strategies, as well as poorer relationship quality and low levels of intimacy, are key influencing factors (Brodaty/Donkin, 2009).

### Positive effects of caregiving on informal dementia caregivers

Most research to date has focused on the negative consequences of caregiving. However, the shift in discourse toward positive perspective on dementia caregiving has prompted an increase in studies examining the positive aspects of informal dementia caregiving. By definition, positive aspects are the extent to which caregiving roles are considered inspiring and rewarding, which leads to positive results and enriches one's lived experience. The concept has been described as uplift, gratification, reward, growth, and satisfaction in the literature (Kramer, 1997; Cohen et al., 2002; Williams, 2005; Yu et al., 2018). In their systematic review on the positive aspects of caregiving among family caregivers of individuals with dementia, Yu and colleagues (2018) discuss conditions and factors related to the emergence of these aspects. According to their analysis, positive aspects of dementia care provided by family caregivers form a multidimensional construct comprising four key domains: First, a sense of personal accomplishment and gratification: This involves the successful acquisition of effective and creative competencies to manage caregiving necessities, handling dementia symptoms, and improve the well-being and functional status of the person with dementia. A second domain are feelings of mutuality in a dyadic relationship: Informal caregivers maintain an intimate relationship with the person living with dementia despite the progressive loss of a reciprocal, intimate, and committed relationship. For example, recognising expressions of love, appreciation, and affection in small and subtle gestures or interpreting them as an indication of reciprocity. The third domain, they describe an increase in family cohesion and functionality:

This is perceived when family members work together supporting one another in taking care of a relative and appreciating the shared opportunity to fulfil filial responsibilities.

Experiencing a sense of personal growth and purpose in life is described as the fourth domain of positive aspect. This refers to a positive change in character and philosophy in life initiated by caregiving. For instance, informal caregivers report a higher priority on maintaining social relationships or that they have learned to be more patient, caring, altruistic or emotionally intelligent (Yu et al., 2018). While Yu and colleagues describe positive psychological aspects, even if related to social relationship issues like family cohesion, there are also positive aspects directly linked to social health. For example, informal care for individuals with dementia can help families come closer and bond. Carers often report feeling a deeper connection with the person they care for, which can strengthen family relationships. Sharing the experience and challenges of caring can lead to better communication and collaboration among family members (Lloyd et al., 2016; Yuan et al., 2023). The journey of caregiving may also encourage caregivers to become involved in advocacy and reach out to support groups and self-help communities, leading to the creation of new social ties (ibid.). Additionally, caregivers frequently receive assistance from their social networks, such as friends, neighbours, and local organisations. Caring for others can bring out people's generosity and empathy, which might result in a broader social network (Donnellan et al., 2017).

## 2.2. Informal dementia caregiving in a dyadic perspective

The analytical approach of the research project presented here can be situated in the tradition of dyadic research approaches. Originally, the dyadic approach was first studied within family studies, where researchers recognised that the reality of an intense two-person relationship makes it necessary to look at both of the two actors than analyse them separately (Thompson/Walker, 1982).

This also applies to the close relationship between individuals living with dementia and their primary informal caregivers. For the present thesis, this means that informal caregivers are regarded as individuals in a care dyad (two-person relationship). Indicators of their own person and indicators of the person with dementia are used to evaluate their living and care situations. This approach is based on findings indicating that the everyday living conditions of informal caregivers are shaped to a considerable extent by a) the person with dementia and his or her care and support needs and b) the specific conditions of the care arrangements. The complexity of individual living and care situations can, therefore, be more adequate represented by analysing the caregivers as embedded in dyadic relationship constellations than analysing them as separate actors (Braun et al., 2009; Moon/Adams, 2012; van't Leven et al., 2013; Orsulic-Jeras et al., 2020).

From a sociological perspective, a dyad is defined as an intense social relationship between two persons. The term "intensive" is used to describe a face-to-face relationship that has existed for sufficient time to establish recognisable patterns of interaction (Thompson/Walker, 1982). Prominent dyads in research include, for instance, the spousal relationship or the relationship between children and their parents. At the centre of a dyadic perspective lies the concept of social relationship. Social relationships can be understood as having appraisal, functional, and structural components (Figure 1). Appraisal is about the quality of the relationship and interactions. Social relationships can be perceived as positive or negative. This domain refers to perceptions and interpretation of the dyad partners involved. The functional component refers to actual exchanges between the dyad members and the underlying purpose. For example, the type of social support (e.g., informational, emotional, esteem, or tangible support). Structural features refer to the infrastructure built by previous interactions, imprinting current and future interaction. Among others, the size of the social network, relationship types, or individual characteristics of the individuals might be considered as basic infrastructure markers (Vernooij-Dassen et al., 2022). This thesis is concerned with structural aspects of the dyadic relationship. Dyads can have different meanings as subjects of research (Hummel/Sodeur, 2010). For instance, dyads can be understood as components of a larger network of relations, whose structure can be simplified to the structural forms of the dyads and triads it contains. Furthermore, the dyad might be considered a social context for the actors belonging to the dyad or as a social context for the actors or dyads. Thirdly, dyads may be defined as independent "units" that are made the subject of the statement.

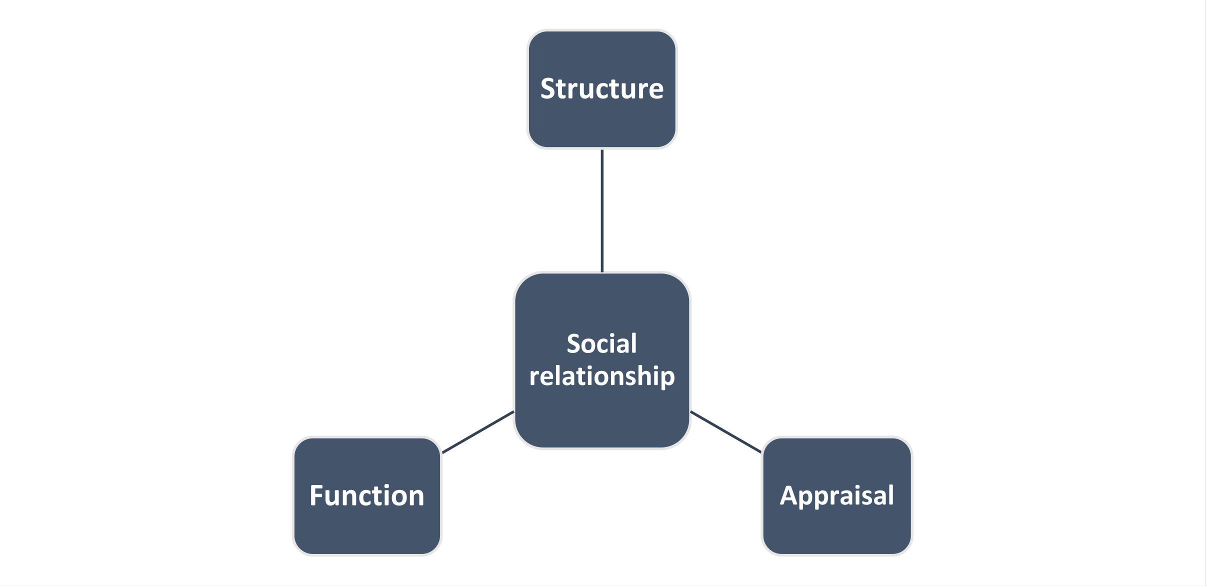

*Figure 1 Basic domains of the social relationship concept (own illustration)*

Lately, dyadic perspectives have become more visible, viewing both parties involved not only as caregivers and care recipients but also placing emphasis on their relationship as care partners or partners in care (Rausch et al., 2017; Hoel et al., 2021; Köhler et al., 2022; Hochgraeber et al., 2023; Hoel et al., 2023). The value of their relationship and closeness is emphasised by people with dementia and their informal carers in several studies (Ablitt et al., 2009). Furthermore, studies of dyads in various contexts suggest that major life stressors affect not only the person in need of care but also those close to them (Orsulic-Jeras et al., 2020). A short summary of key research findings on the structure, appraisal, and function of dyadic relationships in the context of dementia is given in the following paragraphs.

<u>Dyadic structure</u>: In the context of this thesis, the dyadic structure refers to the relationship type or, in other words, the dyadic constellation. This constellation differs depending on who is caring for whom. For instance, the dyadic constellation might consist of an elderly couple living together or a son–father relationship with long spatial distance. Another example would be that caring for a mother living with dementia is taken over by a working daughter, who at the same time still has to ensure the reconciliation of care and work. Such different constellations lead to differing issues and concerns that need differentiated responses (Toseland, 2004).

There are no reliable and generalisable figures on the prevalence of typical dyadic constellations. For most Western countries, it can be stated that the largest number of informal dementia caregivers were spouses, with children and children-in-law following closely behind (European Commission 2018; Wimo et al., 2018). Dementia care is also provided in dyadic constellations with neighbours, friends, or relatives, but these types are rare. Most caregivers are female. However, the proportion of male caregivers is also on the rise (Brodaty/Donkin, 2009; European Commission, 2018). In addition to the type of relationship and the sex ratio, there are other “emerging” socio-demographic sub-differentiations such as the age of both actors, the geographical closeness/distance (Bei et al., 2023; Blackstone et al., 2019; Franke et al., 2019), and the occupation of IC (Sadavoy et al., 2022; Wang et al., 2013; Wang et al., 2011). The dyadic constellation is also influenced by whether other informal people (for instance, friends, family members, neighbours) are involved in the care arrangement (Song et al., 2023; Vernooij-Dassen et al., 2022; Lilly et al., 2013).

There are many studies focusing on different constellation aspects of dyadic relationships in dementia care and their specific needs. Often, the focus is placed on the investigation of single factors, overlooking the genuine complexity of dyadic constellations. Frequently mentioned factors in the literature are, for instance, age (Koyama et al., 2017; Kimura et al., 2021), sex (Robinson et al., 2014; Phillips et al., 2023; Ponsoda et al., 2023), family/kinship relationship (Pinquart/Sörensen, 2011; Smith et al., 2022), housing situation (Abrahams et al., 2018; Brini et al. 2022), or professional activity of informal caregivers (Wang et al., 2011; Neubert et al., 2019), ethnic background (Akarsu et al., 2019; Liu et al. 2021), or social environment features (Karrer, 2016; Gresswell et al., 2018). These studies also illustrate that dyadic constellations require tailored support to promote the psychosocial health of both dyadic actors. This is considered an important element for research on and practical implementation of psychosocial support structures for informal dementia caregivers that regularly finds its way into studies rhetorically but is rarely implemented in a conceptually stringent way (van Mierlo et al., 2012).

Dyadic appraisal: As already mentioned, appraisal primarily concerns the quality of the relationship or quality of the interaction between the person with dementia and the informal caregiver. Essentially, having a good dyadic relationship is not only essential for the psychological and social well-being of both actors but also plays a significant role in the stability of home-based care arrangements (Hochgraeber et al., 2023). Moreover, as summarised from previous studies by Köhler and colleagues (2022), the quality of the dyadic relationship before the onset of dementia is the main factor influencing the caregiver's level of commitment to the carer role. This has relevant implications for the continuity or discontinuity of informal dementia care at home. A positive quality of the previous and current dyadic relationship is indicative of continuity over time. A low well-being in the previous and current dyadic relationship often indicates a stressful experience of the caregiving role and an earlier termination of home care (Köhler et al., 2022). Relationship quality also has significant effects on explaining both the burden and satisfaction of caregiving, suggesting that good quality of relationship can decrease burden and increase satisfaction (Iecovich, 2011; Enright et al., 2020).

Research on dyadic relationship structure in dementia has highlighted differences in the quality of relationships between various types of dyads. To give an example, there might be differences between couple dyads (intra-generational relation) and child–parent dyads (intergenerational relation). Even though there are now studies examining differences between these constellations, most studies fail to do so. Consequently, they overlook specific characteristics that might entail relevant information necessary for developing tailored support (Köhler et al., 2022). Many adult–children caregivers struggle with the normative connotation of caring, such as fulfilling multiple roles. This is especially true for caring daughters and daughters-in-law. Personal, family, moral obligation, and adherence to cultural and societal norms are some of the factors that influence their decision to accept or reject the caring role. Moreover, caring children often have to cope with the dynamics of wider family networks (ibid.). On the other hand, continuing "togetherness" holds greater significance for couples who have been together for a considerable duration than for children being caregivers but are not the life-partners of the individual with dementia (Hochgraeber et al., 2023). Understanding such distinctive features of certain dyadic constellations is crucial in tailoring support and interventions that cater to the unique needs and dynamics of different dyads within the context of dementia caregiving (ibid.). In the same way, it is important to have a closer look at other socio-demographic aspects of dyadic constellations, ideally in a multidimensional model, to use the findings to develop tailored support programmes.

<u>Dyadic function:</u> The functional component of the dyadic relationship refers to different types of social support in a dyadic relationship (Berkman et al., 2000). A distinction is made between the types of social support: emotional, instrumental, and informational support (Kuiper et al., 2016). All three types refer to a person's perception of the availability of help or support from "the other" in a social relationship (ibid.). At the onset of dementia, the way in which social support is provided in a dyadic relationship is strongly characterised by the previous shared biography of the two individuals (Hochgraeber et al., 2023). As dementia progresses, the characteristics of social support in a dyadic relationship begin to change. Typically, the exchange of social support becomes more unbalanced as informal carers take on more and more caring tasks due to the advancing cognitive and physical limitations of individuals with dementia (Xu et al., 2021). In particular, informal caregivers in couple dyads report changes in their relationship with their partner with dementia. Negative changes are reported in areas such

as such as reciprocity, communication, opportunities for, and happiness in the relationship (Rausch et al., 2017). People with dementia emphasise the need for social support to cope with their condition (Bunn et al., 2012).

The forms of social support provided by informal carers are wide-ranging and include emotional, instrumental, and informational tasks (von Kutzleben, 2018). In addition to physical care tasks such as personal hygiene, dressing and undressing, the broad range of tasks also includes housekeeping, taking care of business and official matters as well as social and cultural activities, such as accompanying on walks, visiting family and friends, or organizing and taking part in cultural events (ibid.). There is little evidence to date about differences in social support in the various dementia dyads. Brodaty/Donkin (2009) refer to Archbold's (2003) concept of care providers and care managers to describe what informal caregivers do and where the differences between typical dyadic constellations exist. Care providers provide hands-on care, dressing, assisting with finances, and other daily activities. Care Managers focus on delegation of tasks, for example, a nurse for personal care, an accountant to assist with finances, or volunteers who engage in leisure activities with the person with dementia (Brodaty/Dokin, 2009). Informal caregivers in couple dyads tend to be care providers, and informal caregivers in adult-child parent relationships (and other relatives) are care managers. A result of the meta-analysis by Pinquart/Sörensen (2011), which shows that informal caregivers in couple relationships make less use of informal social support than adult-child caregivers, also fits into this context. Regarding informal caregivers of individuals with dementia, the literature suggests that social support from wider formal and informal networks can help to reduce stress and improve caregiver well-being (Han et al., 2014; Dam et al., 2016; Ruisoto et al., 2020).

Regarding dementia care dyads, this thesis has the following premises: 1) Informal caregivers and individuals living with dementia are a special type of dyad with an intense social relationship and strong reciprocal influences, 2) The dyadic constellation is considered as a key social context for the informal caregivers belonging to the dyad, 3) Dyadic constellations are heterogeneous and differ, for instance, in terms of socio-demographic, relational, and contextual factors, 4) Those differential markers of dyadic constellations contribute to variations in health care-related outcomes and subsequently lead to the need for tailoring support services to dyads with distinct sociodemographic and health profiles.

## 2.3. Accounting for heterogeneity: Tailoring support for dyadic subgroups

The previous explanations underline that the psychological and social impact of informal care varies among informal dementia caregivers. Several studies have suggested that there are important differences between informal caregivers in the extent to which they experience negative or positive outcomes from providing care. So, dyadic care arrangements with informal caregivers providing support for individuals with dementia are heterogeneous, and intervention programmes may be tailored to characteristics of certain dyadic subgroups to be more effective.

The idea of tailoring health care support services to certain target groups with distinct characteristics is rarely novel. This understanding is succinctly summarised by the popular statement "one size does not fit all". But tailoring support to subgroups with unique profiles, so it seems, has mostly not been realised using multidimensional models, but has so far rather been based on focusing on certain individual characteristics of the relevant population (e.g., sex: male, female; relationship: child, partner; living situation: cohabiting, non-cohabiting; geography: urban-rural and so on). More feasible, however, are multidimensional models, especially in the context of dyadic constellations, which try to consider features of the person with dementia, the informal caregiver as well as relational aspects and broader contextual factors. Anyway, which conceptual understandings underpin the concepts of heterogeneity and tailoring in this thesis?

The starting point is that a given population is not homogeneous but rather consists of individuals with distinct characteristics, such as age, gender, race, ethnicity, income, education level, lifestyle, or health status. Heterogeneity is the basis for understanding that people or groups have different characteristics and needs. In general, heterogeneity can be understood as a temporarily attributed inequality that exists between members or parts of members of a group regarding one or more criteria (Boller et al., 2007). The consideration of certain criteria is usually driven by previous evidence-based research results and by the specific epistemic interest of the given study (ibid.). Regarding healthcare needs or preferences of a population this means that it is likely to find different subgroups with different health issues, risk profiles, or preferences for healthcare service use. For instance, a working informal dementia caregiver may require different types of support services than an already very old informal caregiver with health problems of his own. Another example: support needs may differ according to whether a caregiver lives close to the person in need of care or at some geographical distance. The concept of tailoring, in turn, can be understood as a response to heterogeneity. Tailoring methods are widespread in market research and analysis, assuming that a heterogeneous overall market exists with homogeneous subgroups that can be reached with the help of tailored approaches. Tailoring healthcare services is described as a counter-design to standardized care, which is based on evidence-based, disease-specific guidelines (Dekkers/Hertroijs, 2018). Ultimately, the goal of tailoring approaches is to use a profiling process to enable care providers to deliver the right care, to the right person, at the right time.

Overall, the aim of addressing heterogeneity and tailoring health services is to make care more customised to ensure that it is effective and meets the specific needs and characteristics of the individuals targeted. This helps to ensure that health care is more equitable and effective and that health outcomes are improved. From a statistical point of view, tailoring is necessarily based on a data segmentation process. Segmentation is defined as the separation of a given entity into individual elements that can be distinguished from one another according to defined criteria. Segmentation refers to the division of a data set into separate groups or classes, without these classes being known in advance. An increasingly popular method used in quantitative health and health services research as the basis for tailoring approaches is latent class analysis (LCA). LCA can be used to detect and describe so-called latent classes or "hidden groups" within an overall population using a selected set of indicators (Lanza/Rhoades, 2013). These classes can also be thought of as subgroups, target groups, or types that characterise heterogeneity in a population with respect to a particular phenomenon (Scoto Rosato/Baer, 2012). In practical terms, this method uses response behaviour to a given set of questions to identify groups of individuals (here, dyads) that are similar to each other (Nylund-Gibson/Choi, 2018). The approach has already demonstrated its potential in care and nursing research on informal care, e.g., to describe different types of users of health care services, informal care experiences, or support needs, or to study profiles of informal caregivers (Beeber et al., 2008, Janssen et al., 2016, Janssen et al., 2017, Pristavec, 2019, Janssen et al., 2020).

In this dissertation, subgroup differentiation (or target group orientation) will be addressed in various ways. In the 1st article, previous intervention programmes for informal caregivers within dementia care dyads are analysed for their target group orientation and evaluated narratively. In the 2nd and in the 3rd article, model-based subgroups or target groups of dementia care dyads are identified in separate data sets by means of latent class analysis (LCA) and analytically transformed into typologies of home-based dementia care dyads.

### 2.4. Research gaps and relevance of this thesis

To be able to assess the effectiveness of interventions in a valid way, regular systematic analysis of high-quality intervention studies is needed. This is because healthcare decisions for individual patients and for general health policies should be informed by the best available research evidence (Page et al., 2021). A research gap addressed by the first sub-study of this thesis was to provide such an update with a focus on psychosocial interventions to promote mental health on informal caregivers as individuals in home-based dementia care dyads. Another research gap addressed by the first sub-study is the analysis of the subgroup orientation of psychosocial intervention programmes. A stronger focus on specific subgroups of persons living with dementia and informal caregivers in dementia intervention studies has been urged for several years, but is still poorly realised so far (Smits et al., 2007; van Mierlo et al., 2012; Gaugler et al., 2019).

At the core of the second sub-study is the model-based development of a multidimensional subgroup typology of informal dementia care dyads. In addition to identifying different dyad types, the sub-study aims to find out whether membership to a certain type is associated with healthcare-related outcomes. While highlighting socio-demographic characteristics of dyads (individual, relational), this study breaks new ground in dementia caregiving research and aims to contribute towards raising awareness for the relevance of the specific living conditions of informal caregivers in dementia dyads. The analysis of social structures in which informal caregivers as individuals in dyads are situated has also been a minor issue in research on informal dementia care. A few recent studies are increasingly addressing the topic of socio-structural differences in informal caregiving and its consequences, but there are still many open questions for future research, especially within dementia caregiving research (Gresswell et al., 2018; Chen et al., 2016; Karrer, 2016; Jones, 2017).

A third field of research, which is being investigated in an innovative way in this thesis, is that of replication studies. Even though studies in psychosocial care and dementia research have applied latent class approaches, the replication of a LCA in the field of psychosocial dementia care research is novel. This has gained two kinds of insights. On the one hand, this replication provides further verification of the initial findings of the first sub-study. On the other hand, methodological strengths and weaknesses of such a replication approach are discussed and can thus inform further research activities.

# 3. Research questions

## 3.1. Overarching aim and objectives of this dissertation

The overall aim is the identification of typical dyadic relationship constellations in home-based dementia care settings as well as the analysis of similarities and differences regarding relevant health-care related psychosocial outcomes, with a special focus on informal caregivers as individuals in dementia care dyads. The thesis aims to achieve the following four objectives:

***Objective 1***

*To systematically analyse previously implemented psychosocial interventions to support the mental health of informal carers, with the aim of synthesising both their effectiveness and their target-group orientation.*

To contribute to the understanding of best possible support for informal caregivers within specific dyad constellations, it is essential to regularly update the existing evidence on effective psychosocial interventions and their underlying targeting. This objective was achieved in Paper I through a systematic literature review of psychosocial interventions focusing on the psychological health of informal caregivers in home-based dementia care dyads.

***Objective 2***

*To identify and describe typical dyad subtypes and develop a multifactorial dyad typology as well as to analyse similarities and differences between dyad types in terms of relevant health care outcomes.*

So far, there are no approaches analysing and describing typical socio-demographic constellations of informal caregivers in home-based dementia care dyads using a model-based and multifactorial approach and investigating whether and how these dyads differ regarding key health care-related outcomes. By considering both sociodemographic heterogeneity of the target group and health care-related outcomes through the development of a typology, results of such analysis can help tailoring support measures to better reflect needs of certain subgroups. Paper II conducts a secondary analysis of baseline data from a German dementia network evaluation study (DemNet-D) to address this objective, employing a Step-3 Latent Class Analysis.

***Objective 3***

*To determine whether the latent class structure as well as associations with health care-related outcomes of the second sub-study replicate in a structurally similar but distinct sample of informal caregivers and persons living with dementia.*

Replication studies are still carried out too rarely. However, they are of vital importance for controlling analyses that have been carried out once and for testing their reproducibility, especially when the analysis is based on a different population sample. This may provide evidence (increased external validity) to inform the development of more tailored healthcare support services for informal caregivers living in home-based dementia care dyads. This is where paper III comes in, by replicating the methodological and statistical approach of the original German study using cross-sectional data by the Dutch COMPAS study.

# 4. Methodical approach

Different methods were employed in this cumulative dissertation project. This chapter provides a rationale and details the methodical approach.

## 4.1. Systematic literature review

The aim of the first part of the thesis was to generate a systematic overview of the characteristics and effectiveness of recent psychosocial interventions aimed at promoting the mental health of informal caregivers in home-based dementia care dyads. A special focus was additionally placed on analysing the reported interventions concerning their focus on tailoring programs to specific subgroups of informal caregivers. For example, whether the intervention is specifically designed for caregiving partners or children, male caregivers, rural situations, or for the needs of distance caregiving.

Evidence syntheses, i.e., summaries of research results as systematic reviews, facilitate the identification of relevant findings for a specific research question at a glance and are suitable, for instance, for identifying gaps in research (Page et al., 2021; Grant/Booth, 2009). Hence, this approach was chosen for the first part of the thesis. Systematic reviews usually focus on presenting knowledge from individual studies in aggregated form. With the resulting basis of results, precise questions can usually be answered with greater significance. Reviews often also include an assessment of the study quality of included studies (Page et al., 2021). It is essential that systematic reviews follow a precisely defined methodology to ensure that the results are reliable. The methodological approach of a systematic review should be transparent, complete, and comprehensible for readers in a way that allows the replication of the review study (Moher et al., 2018). The approach should be described in detail using standard reporting guidelines (Page et al., 2021; Moher et al., 2018).

For the further sub-studies of this thesis, the first sub-study should achieve two objectives:

- Description and analysis of design and effectiveness of psychosocial mental health interventions for informal caregivers in home-based dementia dyads.
- Analysis of target group orientation of the intervention programs to assess whether the applied methods are adapted to the heterogeneity/diversity of the target group.

A meta-analysis of all included studies was not planned due to the heterogeneity of the included mental health outcomes and measures applied, as well as the variety of reported effect parameters. For the analysis of the target group orientation of the interventions, a specific examination of the selected studies in the form of a meta-analysis was not suitable.

## 4.2. Latent class analysis

In the second sub study, the issue of heterogeneity of the population of informal caregivers in home-based dementia care dyads was explored in more depth. The systematic review revealed a paucity of tailored intervention programmes for specific subgroups of informal caregivers in home-based dementia care dyads. The objective of the second sub-study was to investigate the typical sociodemographic subgroups that exist in home-based dementia caregiving dyads, and whether psychosocial needs vary among those subgroups. In order to accomplish the objectives, a latent class analysis was carried out. The German DemNet-D study's baseline data (n=551) served as the data source for the latent class analysis (LCA) conducted in the second sub study. The DemNet-D project was a multi-sited and multidisciplinary evaluation study (2012–2015) that investigated the care and living situation of community-dwelling persons living with dementia and their informal caregivers as service users of thirteen regional dementia networks (DCN).

### 4.2.1. Data preparation

To conduct a latent class analysis, data needs to be prepared appropriately. The following sections present the crucial steps of data preparation. First, the data was cleaned. Originally, the DemNet-D dataset includes 560 dyads. For the purpose of this study, focused on informal caregiving, data from nine dyads were excluded. This was done because professional guardians or other formal caregivers provided information. Thus, the present study includes data from 551 community-dwelling dyads (551 persons living with dementia, 551 informal caregivers). Second, as LCA needs categorical data, the original DemNet-D data was transformed systematically (Wolf-Ostermann et al., 2020). Third, regarding the handling of missing data, it is assumed that the missing values are "missing at random" (MAR). This assumption implies that the estimated parameters of the model remain unbiased (Vermunt/Magidson, 2021). Therefore, no data imputations were performed.

### 4.2.2. Statistical analysis

LCA belongs to the group of finite mixture models (FMM) and is a person-centred approach (Nylund-Gibson/Choi, 2018; Masyn, 2013). FFM assume that a specific population comprises more than one hidden subgroup. Membership in a particular subgroup is dependent on the response pattern to a set of items. LCA is used to explain heterogeneity in a population by identifying distinct latent classes (class separation). However, the individuals within each class are similar regarding a set of observed indicators (class homogeneity) (Kongsted/Molgaard, 2017; Lanza/Rhoades, 2013). There are various kinds of LCA, and depending on the research issues, the appropriate procedure must be determined in advance. The Step3 approach with distal outcomes was the preferred model for this study.

Step3-approach with distal outcomes

There were two main objectives for the second sub-study of this thesis. The first objective was to identify latent classes within the DemNet-D dataset. The second objective was to explore whether there were significant differences in relevant health care-related outcomes between the identified classes, which could be attributed to the indicator variables that had been used to form the classes. In other terms, the study aimed to identify different dementia dyad constellations and determine whether there were statistically relevant variations between these constellations in terms of psychosocial health outcomes and the use of health care services. The three-step latent class approach with distal outcomes was designed for this kind of research interest (Vermunt/Magidson, 2021). This method is superior to the one-step approach and allows for the identification of subgroups first, subsequently exploring how a latent variable (here, the dyad type) relates to external factors (here, healthcare-related outcomes). The Figure 2 provides a visual representation of the latent class model that includes a distant outcome (Lanza/Tan, 2013).

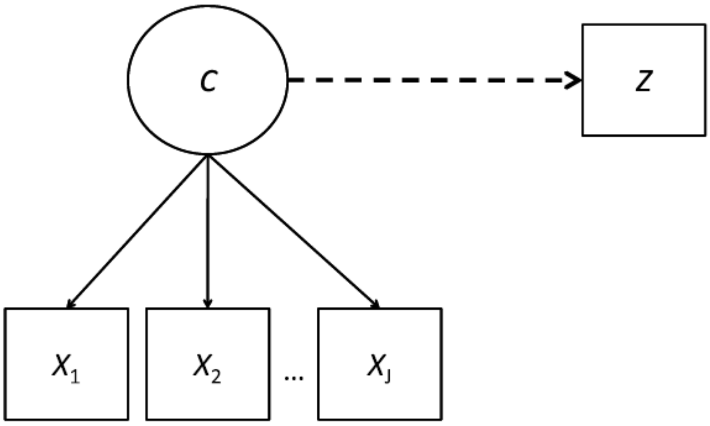

Figure 2 Graphical representation of the latent class model with a distal outcome.

The figure briefly explained: The “C” refers to the latent class variable (dyad constellation subgroup), “X1,” “X2,” ..., “XJ” refer to manifest indicators of “C” (sociodemographic indicators forming the subgroup), and “Z” refers to the distal outcome (health-related outcome). The 3-step method includes these steps:

- First, a best-fit latent class model is established for a group of indicator variables.
- Next, individual cases are probabilistically assigned to the latent classes.

- Lastly, the probability scores are used to evaluate the association between latent class membership and the chosen distal outcomes. To avoid bias, the associations are adjusted for classification errors (Masyn, 2013).

Procedure of the LCA

In a first step (step-1), the number of clusters "C," the cluster size and the cluster structure are estimated. A hierarchically sorted list, see Table *2* below, of indicator variables, "Xj," formed the basis for this. Throughout the process, decisions regarding the inclusion of a new indicator variable are made step by step, only after examining all higher-ranking indicator variables. The indicator variables were included in the model systematically, according to the algorithm described below.

*Table 2 Hierarchy of indicator variables for LCA analysis*

| **Level 1 indicator variables** |
|---|
| Age in years informal caregiver |
| Age in years persons living with dementia |
| Informal care relationship |
| Sex informal caregiver |
| Sex person with dementia |
| Living situation of dyad |
| **Level 2 indicator variables** |
| Size of further informal support |
| Occupation informal caregiver |
| Social class (Scheuch-Winkler Index) |
| Time caregiver spent for care and support (RUD) |
| Duration of care (in years) |
| **Level 3 indicator variables** |
| Instrumental activities of daily living (IADL) |
| Agitated behaviour (CMAI) |
| Dementia severity (FAST) |
| **Level 4 indicator variables** |
| Regional socio-economic deprivation (GISD) |
| Regional care and medical infrastructure |

As a first step, a hierarchy of indicator variables has been established. Then, in a second step, a LCA was conducted with the six indicator variables of level 1, namely, gender of the informal caregiver, gender of the person with dementia, age of the informal caregiver, age of the person with dementia, informal care relationship, and living situation of the dyad. The optimal number of classes (subgroups) was determined and fixed using the BIC (Bayesian Information Criterion) values. To determine whether the impact of individual indicator variables in the model was significant, two statistical tests were employed:

- Wald Test: Within the framework of an LC regression, this test examines whether regression coefficients within all classes are equal to zero (null hypothesis test). In other words, the null hypothesis is that there is no significant difference between classes (subgroups concerning the respective indicator variable Xj (health care-related outcome of interest) (Liao, 2004).
- Likelihood Ratio Test (LRT): This analyses whether the model with the final number of indicator variables is a significantly better version than the model with an indicator variable less (null hypothesis test) (Chen et al., 2020).

Thirdly, additional indicator variables were stepwise added to the model. If an indicator variable improved the latent class model's fit significantly, it was integrated into the model. If it doesn't, it was discarded for the final model, and the next indicator variable was tested for model inclusion. Ultimately, the final model's fit, with all clusters and integrated indicator variables, was evaluated using the BIC to determine if it adequately fitted the data.

Once the number of classes, cluster size, and cluster structure have been estimated in step 1, the adjusted 3-step LCA method is used to evaluate the association between classes and outcome variables in steps 2 and 3. Latent Gold 5.1 uses the Modified Bolck-Croon-Hagenaars (BCH) method for the analysis (Bakk et al., 2013).

### 4.3. A latent class analysis replication

In essence, a replication study involves duplicating a research procedure as closely as possible in a subsequent investigation (Gould, 2002). The subsequent investigation is carried out in a different setting with different populations to determine the degree to which the findings can be applied to a broader context (Nosek, 2020). If researchers are able to reproduce the results of a study, it can lend greater credibility to the findings. Successful replications indicate that the findings are more likely to be applicable to larger population groups. Overall, studies of this nature may facilitate the accumulation of evidence, which can be used to develop and implement improved healthcare delivery systems (Gould, 2002; Nosek, 2020).

In social research, many researchers agree that replication studies are not conducted and published frequently enough (Bohannon, 2015; Makel et al., 2012). Unfortunately, people often mistakenly believe that these studies are less creative or worthless and are considered less important than other studies (Gigerenzer, 2018; Lindsay/Ehrenberg, 1993; Neuliep/Crandall, 1993). Replication studies can be differentiated based on whether they analyse a) the same or b) alternative data using c) the same or d) different methods. This study used alternative data (b) and the same methodical approach (d) and can, therefore, also be referred to as exact or direct replication (Steiner et al., 2019). We followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for conducting and reporting this study (von Elm et al., 2008).

### Data preparation and statistical analysis

In the context of replication studies in the social sciences, 'data preparation and harmonisation' refers to the process of collecting, cleaning, organising, and making consistent the data used in a study that aims to replicate the findings of a previous research project. This is essential to ensure that the replication study follows the same procedures and analyses as the original study, allowing researchers to assess the validity and generalisability of the original findings.

The aim of the third sub-study was to replicate the methodological and statistical approach of the DemNet-D LCA (the second sub-study) with a new sample from a different country. For this purpose, we used the structurally and thematically similar Dutch COMPAS dataset, a mixed method prospective observational and controlled cohort study from the Netherlands (MacNeil Vroomen, 2012). Data were offered for the replication study by COMPAS study coordinator (Prof. Dr. Hein van Hout). A cooperation agreement was made and data provided via SURFdrive, a cloud service for the Dutch education and research. In addition, further support was provided by Prof. Dr. Hein van Hout for additional queries in the context of data cleaning, organisation, and harmonisation.

The first step was to decide, in the light of the original study, which variables or which specific aspects of the COMPAS study data would be used for replication. Then, data issues were identified and corrected to ensure the accuracy and reliability of the dataset. The original COMPAS data set includes 521 dyads. Twelve dyads were removed because data was missing on at least half of the indicator variables used for feeding the LCA to identify the dyad classes. Data had to be harmonised and transformed to ensure that variables with the same or similar meanings are standardised across sources, allowing for meaningful comparisons. For organising the data, variable names and labels were aligned with the terminology used in the original study to maintain consistency. As far as appropriate, the same was done for the variable codes, units of measurement, data format, and structure. Moreover, the handling of missing values was adapted to the procedure of the original LCA. All indicators and distal outcomes used in both studies can be directly compared in the supplementary information (Additional file 2) of the published 3rd article of this thesis (Wiegelmann et al., 2023). Regarding the statistical analysis, latent Gold 6.0 was used for all analyses. A bias adjusted step 3 LCA model with distal outcomes was used to identify meaningful subgroups of dementia care dyads and their impact on health-related outcomes. The same methodological and statistical procedures were applied as in the original study. Table *3* below shows the indicator variables used to detect the latent dyad subgroups within the replication LCA.

*Table 3 Hierarchy of indicator variables for LCA replication*

| **Level 1 indicator variables** |
|---|
| Age of informal caregivers |
| Age of individuals living with dementia |
| Informal care relationship |
| Sex of informal caregivers |
| Sex of individuals living with dementia |
| Living situation of dyad |
| **Level 2 indicator variables** |
| Further informal support |
| Paid work of informal caregivers |
| Education of individuals living with dementia |
| Time informal caregivers spent for care and support |
| Start of dementia symptoms |
| **Level 3 indicator variables** |
| Activities of daily living (Katz ADL-15) |
| Neuropsychiatric Inventory (NPI) – 3 Items |
| Mini Mental Status Examination (MMSE) |
| **Level 4 indicator variables** |
| Regional socio-economic status (RSES) |

After the statistical analysis, the interpretation of class structure and interrelations with health-related outcomes, the results of both studies were compared in a narrative way. This ensured a specific assessment of similarities and differences between the two LCA.

## 5. Key findings of the three publications

To achieve the research goals, a series of three studies was carried out. A systematic literature review on psychosocial interventions to support the mental health of informal caregivers of persons living with dementia was conducted as a first step. The results are presented in the first publication *Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia—A systematic literature review* (Wiegelmann et al., 2021a). The second article builds on the findings of the first article. Titled *Dyadic subgroups in dementia caregiving—A latent class analysis of home-based care arrangements* (Wiegelmann et al., 2021b), it addresses the identified deficit of effective target group-specific dyadic-oriented interventions to promote the mental health of family caregivers of persons living with dementia and develops a model-based multidimensional typology of six dementia care dyad subgroups with description of their central characteristics and health-relevant outcomes using cross-sectional data from the German research project DemNet-D and latent class analysis. The third study is designed as a replication study of the second study. With the title *Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads—A latent class replication study* (Wiegelmann et al., 2023), it replicates the method and statistical approach using a structurally similar but distinct data set from the Dutch COMPAS study.

### 5.1. Effectiveness and target group orientation of mental health interventions

The first publication (Appendix I) *Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia—A systematic literature review* (Wiegelmann et al., 2021a) systematically reviews empirical evidence from high quality randomized controlled trials (RCTs) about psychosocial interventions and their effectiveness focusing on major mental health parameters to promote the health of informal caregivers of persons with dementia living at home in the community. Furthermore, an analysis of the subgroup orientation (tailoring) of interventions is presented.

The methodical approach was documented using the PRISMA 2009 checklist. Articles published between 2009-2018 were systematically searched and retrieved from the electronic databases PubMed, PsycINFO, Scopus, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) in August 2018. Studies were included if they investigate at least one of the following clinical outcomes: depression, burden, quality of life, well-being, anxiety, stress, grief, or mood. We included only RCTs because they are widely considered to be the most rigorous method for assessing the efficacy of an intervention. The interventions must aim primarily on supporting the mental health of informal caregivers. The reporting of the intervention programme must be sufficiently detailed with regard to content, duration, sessions/contacts, medium(s) used, location, group or individual approach, target group. Furthermore, only studies with high methodological quality according to criteria based upon Cochrane Collaboration Guidelines were included. Two reviewers independently screened the articles and rated the methodological quality of the studies included.

Finally, 48 publications reporting on 46 unique intervention programmes met the selection criteria and were included in the classification and evaluation (synthesis). Even though only studies with high methodological quality were included, the samples illustrate that there is still room for further improvement in future research, such as increasing sample sizes to perform detailed subgroup analyses or conducting long-term follow-ups. Subjective caregiver burden, depression, and QoL are the predominant mental health parameters that were investigated. Overall, twenty-five of forty-six interventions (54.3 %) show positive effects on at least one of the outcomes examined. Most positive effects, in terms of the success rate (proportion of studies with positive effects compared to the total number of studies on the outcome), are reported for the outcome subjective caregiver burden. Cognitive behavioural approaches show promising results, especially concerning the reduction of depressive symptoms. Besides this, leisure and physical activity intervention and, with some limitations, psychoeducational approaches, seem to contribute to reducing subjective caregiver burden. Only six studies explicitly target on a certain subgroup of informal dementia caregivers (13 %), whereas all other interventions (87 %) target the group as a whole without differentiation.

The studies in this review show a limited focus on certain dementia caregiver subgroups. We would like to underline the potential that might be found in a consistent targeting of interventions to specific subgroups. This relates to the structure, content, and delivery of intervention programmes in order to improve their compatibility and thus increase the likelihood that they will be beneficial to informal caregivers in dementia care dyads. Additionally, this study suggests the importance of carefully considering the outcomes being targeted. For example, based on our results, we can cautiously conclude that interventions involving leisure and physical activity are effective in reducing the subjective burden experienced by informal caregivers. Cognitive behavioural programmes are shown to be predominantly effective in treating depressive symptoms. From a methodological perspective, it is important to pursue longer follow-up intervals and larger study samples.

## 5.2. Developing a typology of community-dwelling informal dementia care dyads

The second article (Appendix II), *Sociodemographic aspects and health care-related outcomes: a latent class analysis of informal dementia care dyads,* expands on previous studies that highlight the importance of addressing informal caregivers in a differentiated manner and tailoring support services according to heterogenous living and care circumstances of certain dyad constellations (Wiegelmann, 2021b). As a result, this research aims to firstly identify subgroups of dementia care dyads that differ in sociodemographic, care-related, and dementia-specific characteristics. Secondly, the study compares dyad subgroups concerning healthcare-related results.

Data from the cross-sectional German DemNet-D study (n = 551) was used to investigate different classes of dementia care dyads using latent class analysis. Additionally, we compared these classes based on factors such as the use of health care services, caregiver burden, general health of the informal caregiver, as well as the QoL and social participation of the person with dementia. Considering the study population, people living with dementia were on average 79.5 years old. Over half of them were female (57 %). Informal caregivers were on average 64 years old, and 75 % of them were female. 62.4 % had no professional occupation. 61 % of the dyads lived together, and 50.6 % were in a couple relationship.

Based on Bayesian Information Criterion (BIC), a significant likelihood ratio test ($p < 0.001$), high entropy (0.87), and substantive interpretability, the model fit and interpretation supported a model with six dementia care dyad classes as the most precise solution. The latent class analysis resulted in a final best-fitting model solution with six classes, based on 15 significant indicator variables ($p < 0.05$). To further characterise the dyad classes, we utilised only the indicator variables explained best by the model ($R2 \geq 0.3$). Those indicators included 1) sex of the person with dementia, 2) age of the person with dementia, 3) sex of the informal caregiver, 4) age of the informal caregiver, 5) occupation of the informal caregiver, 6) informal care relationship, and 7) dyadic living situation. Following the main class-building indicators, classes were labelled as "adult child parent relationship & younger informal caregiver" (class size: 22.9 %), "adult child parent relationship & middle-aged informal caregiver" (class size: 17.1 %), "non family relationship & younger informal caregiver" (class size: 8.8 %), "couple & male informal caregiver of older age" (class size: 14 %), "couple & female informal caregiver of older age" (class size: 31.4 %), "couple & younger informal caregiver" (class size: 5.8 %). The classes showed significant differences regarding the rate of health care service use (the use of medical information sources and the use of informal information sources). Further significant differences were observed regarding subjective informal caregiver burden. In this context, the results show that dyads may face different dimensions of burden (according to BIZA-D PV subscales), which in turn points to the need for different support strategies. The general health status (EQ VAS) of the informal caregivers is lower in the intragenerational spousal relationships (classes 4, 5, 6) than in the intergenerational adult-child parent relationships (classes 1, 2, 3). The QoL (QoL-AD proxy) of the person with dementia differed also significantly between the classes, with better QoL in dyads with adult-child caregivers compared to spousal relationships. The stability of the dyadic care arrangement (SoCA) differed also significantly between the classes, which, however, was difficult to interpret with the data available and needs further investigation. No significant differences were found for other outcome parameters

In intervention research, informal caregivers as individuals in dementia care dyads are frequently conceptualised as a relatively homogeneous group, while their diversity in terms of personal, dyadic-relational. and other aspects that determine living and care situations often remain invisible (van Mierlo et al., 2012; Smits et al., 2007; Toseland, 2004; Barber et al., 1995). This study, based on a latent class analysis, reveals that the dyadic constellations in which informal carers act as key protagonists of care arrangements are distinct in terms of both individual and dyadic-relational factors. The most important characteristics that distinguish the classes are the relationship between the informal carer and the person with dementia (marital relationship, child-parent relationship, non-family relationship) and the age of the informal carer (young, middle-aged, elderly). Furthermore, the dyad classes differ considerably regarding gender relations, living situation and employment status of the informal caregivers. The study findings suggest that these differences between care dyads should be carefully considered in the design and implementation of counselling and further psychosocial, therapeutic or nursing support services. The proposed typology allows for a multidimensional description and thus a more comprehensive representation of dyadic subgroups in home-based dementia care. The results point to the need to target dyadic subgroups in terms of counselling, promotion of service use and caregiver burden reduction. The findings might provide guidance for better tailoring of support services to the particular circumstances of dyads, resulting in improved health-related outcomes for informal carers in dementia care dyads.

### 5.3. Replicating a typology of community-dwelling informal dementia care dyads

The third study (Appendix II), *Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads: a latent class replication study* replicates the second sub-study (Wiegelmann et al., 2023). Its objective is to reproduce the subgroup typology of dementia dyads with the closest possible duplication of the methodological and statistical procedures. This was based on a data set of a Dutch home-based dementia care dyad population that was distinct but structurally similar. The results should show whether the findings from the first sub-study are likely to be generalisable, especially as the sample in this second study is drawn from a different population. This could provide evidence (greater external validity) on which to base better-tailored psychosocial health care support services for community-dwelling informal caregivers in dementia care dyads.

We applied LCA to the baseline data of the COMPAS study, a prospective cohort study. The data consists of 509 people with mild to moderate dementia living in the community and their informal caregivers. A 3-step LCA approach was used to examine the association of the classes with health outcomes, and descriptive approach was used to compare the latent class structures of the original and replication studies. These health outcomes were assessed: health care service use, mental health and burden of the informal caregivers, QoL of the person living with dementia as well as unmet needs as proxy to assess the stability of home-based care arrangements. In COMPAS LCA, individuals living with dementia were on average 79.7 years old, and more than half were female (55 %). The mean age for informal caregiver was 64.5, and two-third were female (66.6 %). In addition to their caring responsibilities, 38.9 % were also engaged in paid employment. Most dyads were in couple (51.9 %) or adult–child relationships (40.3 %), and most dyads lived together (54 %).

When compared to the original LCA dataset, the distribution of the most relevant indicators for class formation (with $R^2$ values close to or above 50 %) is similar for the age of informal caregivers, the age of individuals with dementia, the informal care relationship, the sex of individuals with dementia, and the work status of informal caregivers—when combining full-time and part-time work as in the original study. However, notable differences exist in the percentage of male caregivers (33.4 % in this study compared to 25 % in the original study) and living arrangements (61.2 % living together in this study compared to 54 % in the original study). Models with varying numbers of classes (1-9) were compared, and, in line with the original study, a 6-class solution provided the best fit for the data. As per the original LCA, the best-suited model was selected on the basis of fit indicators (BIC, LRT, Entropy) and meaningful interpretability. Again, as in the original study, the replication study showed a 3-class model with good fit statistics, especially in terms of model improvement. However, the fit statistics preferred the 6-class model to the 3-class model, and the former was also interpretable. Whereas in the original study 15 out of 16 indicators were significant, in this study only 12 out of 17 indicators were found to be significant. To match the approach of the original LCA, only the indicator variables explained best by the model (R2 ≥ 0.3) were used for further characterizing the dyad classes. These were: 1) age of individuals living with dementia, 2) age of informal caregivers, 3) informal care relationship, 4) sex of individuals living with dementia, 5) sex of informal caregivers, 6) living situation, 7) paid work of informal caregivers.

Using the most relevant class-building indicators, classes were labelled as follows: a class of "adult-child-parent relation with younger informal caregiver" (class size: 31.8 %), a "couple with female informal caregiver of older age" group (class size: 23.1 %), an "adult-child-parent relation with middle-aged informal caregiver" class (class size: 14.2 %), a "couple with middle-aged female informal caregiver" class (class size: 12.4 %), a "couple with older male informal caregiver" group (class size: 11.2 %), and a "couple with middle-aged male informal caregiver" class (class size: 7.4 %).

Regarding health care-related outcomes, people with dementia living with a spouse reported better QoL than those with adult children as dyadic care partners. The worst health condition was reported in groups where female informal caregivers lived with male persons with dementia in a spousal relationship. Those groups that involved older female informal caregivers in a couple relationship reported the most severe physical and mental health burden. Unmet needs are most often reported among classes 1 and 3, both dyad types in intergenerational adult-child parent relationships, not living together, and with relatively young informal caregivers.

The best model was selected for both studies based on the statistical fit indices BIC, Entropy, and LRT. Moreover, a robust interpretation was necessary for the best statistical solution. Both studies resulted in a 6-class model solution that best fit the data using this harmonised approach. There are similarities but also differences between the first latent class study and the second replication study in terms of the factors that formed the six classes. In general, the original study revealed three couple classes and three adult-child parent classes, whereas the current study identified four couple classes and two adult-child parent classes. Three out of six classes show structural similarities in the comparison of both LCAs despite differences. However, there are also differences. Unlike in the first study, two classes of male informal caregivers emerge in the second study. Likewise, the second study shows a second class of female informal caregivers in couple relationships, which was not the case in the first study with only one class of this type. Two classes were identified in the original LCA, which do not appear in the replication LCA. First, a small class with predominantly non-kinship and distant caregiving relationships, and second, a class with younger couples.

In conclusion, this study, utilizing two distinct but structurally similar datasets, identifies significant subgroups within dyadic dementia care constellations. These subgroups, characterised by key indicator variables, including age, sex, informal care relationship, living situation, and caregiver occupation, demonstrate notable differences in healthcare outcomes. Tailoring support services to address these variations is crucial for enhancing the well-being of individuals with dementia and alleviating the burden on informal caregivers. The DemNet-D study and the COMPAS study were designed and conducted independently of each other in different national contexts. The observed differences between the two populations and the measurements used are thus not surprising. The results of the third sub-study can also be interpreted against the background of these differences. For future research, it would be conducive to develop a core set of sociodemographic and relational indicators that is generally accepted, so that individual findings can be replicated more accurately.

### 5.4. Summary of key findings

Both the analysis of the international literature on mental health interventions for informal caregivers in home-based dementia caregiving dyads and the two latent class analyses conducted for this study provided insights into a) the psychosocial health of informal dementia caregivers, b) typical constellations of informal caregivers within dementia care dyads, and c) subgroup-specific analysis of psychosocial health and approaches for providing tailored support. Results of the systematic overview have shown that so far only few interventions have an explicit subgroup orientation. These few studies focusing on certain informal dementia caregiver subgroups revealed that the intervention programmes (structure, content, delivery) lack a detailed focus on central characteristics of the respective target group, or at least this was not reported in the publications examined. The subgroup orientation of the programmes thus appears to be rather of a rhetorical nature. This underscores the research interest of this thesis: to develop a model-based typology of dementia care dyad constellations and to examine them for relevant differences with regard to health care-related outcomes.

In both studies, six distinct classes were identified, with the indicator variables 'informal care relationship' ($R^2 = 0.812$) and 'age of informal caregivers' ($R^2 = 0.811$) showing the highest explained variance. Notably, whereas the original study identified three couple subgroups and three adult-child-parent subgroups, the present study identified four couple groups and two adult-child-parent groups. The two largest subgroups remained consistent across both studies.

"Adult-child-parent relationship & younger informal caregiver" and "Couple & female informal caregiver of older age," collectively accounting for about 55 % of the cases in both studies. The German LCA uncovered a small class (class 3, size: 8.8 %) characterised mainly by non-kinship and long-distance care relationships. Additionally, the original study identified a class featuring younger couples, indicative of early-onset dementia scenarios (class 6, size: 5.8 %).

Regarding healthcare service use, both studies showed that dyads with intergenerational adult-child-parent relationships were more likely to use care services. A consistent pattern emerged concerning the general health status of informal caregivers in both studies. Informal caregivers involved in couple relationships had poorer health scores, with the worst scores found in structurally analogous classes 2 (Dutch sample) and 5 (German sample), both representing couple relationships with older female caregivers. High caregiver burden scores were associated with the poorest health status in informal caregivers in both studies. This trend was most prominent in couple relationships, especially when the caregiver was an older woman. This accumulation of adverse health indicators highlights specific risk profiles within certain groups and the need for targeted support services.

Although there are differences in the methods used, an interesting finding is that the group in the German sample with the most unstable care arrangements also has the most unmet needs in the Dutch sample. In both studies, this highlights the need for tailored support that addresses the unique challenge of combining work and care responsibilities. Across both the initial study and its replication, the lowest QoL scores was reported by adult-child informal carers in classes with the oldest people with dementia. Conversely, couples living together showed better QoL ratings. Given the importance of QoL as a primary outcome in dementia care, it is essential to focus on groups with relatively lower QoL levels.

It should be acknowledged that the methodological limitations of the replication approach prevent strong conclusions being drawn about typical dyadic constellations and their associations with health-related outcomes. Besides similarities across studies, relatively large differences were also found. Further research is required in this area, particularly using larger datasets consisting of core variables to facilitate more accurate replication studies. Table 4 provides a summary of the relevant results of each individual study.

*Table 4 Summary of the three individual studies and embedding in the overall context*

| Guiding research questions | Database and methodology applied | Key findings | Embedding in the overall context |
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| ***Study 1: Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review (Wiegelmann et al. 2021a)*** | | | |
| ▪ What kinds of interventions have been implemented to improve mental health outcomes of informal caregivers of persons living with dementia?<br>▪ What effects on mental health outcomes are described?<br>▪ What are the specific subgroups of informal caregivers the intervention programmes relate to?<br>▪ What effects are reported for interventions targeting a particular subgroup? | ▪ Systematic literature review.<br>▪ RCTs focusing on a mental health outcome and describing a psychosocial mental health program for informal caregivers of persons living with dementia.<br>▪ Databases: PubMed, PsycINFO, Scopus, CINAHL.<br>▪ Two reviewers screened independently.<br>▪ Critical appraisal using criteria established by Brodaty et al., (2003) based on Cochrane Collaboration Guidelines. | ▪ 48 articles regarding 46 intervention programmes met the inclusion criteria. The main parameters that were investigated are burden, depression, and QoL.<br>▪ 54.3 % of the 46 interventions (25 in total) showed positive effects on at least one of the outcomes examined.<br>▪ Positive effects are most commonly reported for subjective caregiver burden (46.2 %).<br>▪ Only 6 studies explicitly target a certain subgroup of informal dementia caregivers (13 %). All other interventions (87 %) target | ▪ Cognitive behavioural approaches show promising results, especially concerning depressive symptoms reduction.<br>▪ Leisure and physical activity interventions and psychoeducational approaches, seem to reduce subjective caregiver burden.<br>▪ Based on the analyses carried out in this review, we suggest that subgroup orientation is not adequately implemented in intervention studies<br>▪ The limited subgroup orientation in the intervention studies led to the decision to analyse typical subgroup constellations of IC in dementia care dyads in a |

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| | | the group as a whole without any reported differentiation.<br>▪ Only one outcome (quality of life; QoL) out of nine mental health outcomes studied showed positive effects for the informal caregivers in the intervention group. | further study and to determine whether they differ in terms of relevant health care-related outcomes and thus also in their support needs. |
| ***Study 2: Sociodemographic aspects and health care-related outcomes: a latent class analysis of informal dementia care dyads (Wiegelmann et al. 2021b)*** | | | |
| ▪ What classes of dementia care dyads can be identified to develop and provide a comprehensive description of a multidimensional typology?<br>▪ How do the identified subgroups differ from each other in terms of healthcare-related outcomes? | ▪ Non-randomised cross sectional study using baseline data from the German DemNet-D study (n=551).<br>▪ DemNet-D: Multicentre longitudinal study (2012-2015) with one-year follow-up.<br>▪ The data collection was carried out by specially trained interviewers at participants homes<br>▪ Data analysis: Latent Class Analysis (LCA) using categorical data, Step3 approach. | ▪ As in the original LCA six different classes of dyads were identified, also based on best Bayesian Information Criterion (BIC), significant likelihood ratio test ($p < 0.001$), high entropy (0.87) and substantive interpretability.<br>▪ 15 indicators ($p < 0.05$) were included in the final model<br>▪ For further characterisation of the dyad classes, only those whose variance was best explained by the model ($R2 \geq 0.3$) were used: Sex and age of both actors, occupation of the informal caregiver, | ▪ Six meaningful subgroups of informal caregivers in dementia care dyads were identified.<br>▪ Dyads differed regarding individual (gender, age, occupation) and relational factors (informal care relationship, living situation).<br>▪ Dyads differed also regarding healthcare-related outcomes (service use, QoL, caregiver burden, health of informal caregiver, stability of care arrangement)<br>▪ The results suggest that differences among care dyads should be carefully reviewed |

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| | | informal care relationship and dyadic living situation.<br>▪ The classes showed significant differences regarding health care service use.<br>▪ Caregiver burden, QoL of the person with dementia and stability of the care arrangement differed also significantly between the classes. | in the design and implementation of counselling and support services.<br>▪ A latent class approach can offer important insights into key subgroups of the target population in order to tailor prevention, treatment and psychosocial support programmes to meet their needs.<br>▪ Nevertheless, LCA is data-driven and somewhat subjective in its interpretation. Therefore, the aim for the third sub-study was to repeat the methodological and statistical approach using a different but structurally similar data set to see to what extent the class structure and associations with outcomes can be replicated. |
| ***Study 3: Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads: a latent class replication study (Wiegelmann et al., 2023)*** | | | |
| ▪ Which latent classes of informal dementia care dyads can be identified in the Dutch COMPAS dataset using the | ▪ Non-randomised Cross sectional study using baseline data from the Dutch COMPAS study (n=509). | ▪ As in the original LCA, 6 distinct dementia dyad subgroups were identified | ▪ As in the second sub study, a model with six subgroups fitted the data best. |

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| same methodological and statistical approach of the original German study?<br>▪ What are the similarities and differences regarding health care related outcomes (i.e., quality of life, burden of care, unmet needs) between the Dutch latent classes?<br>▪ What are the similarities and differences when comparing the latent classes of the German original study and the present Dutch replication study? | ▪ COMPAS: 2-year prospective, observational, controlled, cohort study<br>▪ Interviews conducted at participants homes by trained interviewers using case record forms.<br>▪ Data analysis: Latent Class Analysis (LCA) using categorical data, Step3 approach, narrative replication analysis | (based on BIC, LRT, Entropy).<br>▪ 12 indicators contributed significantly ($p < 0.05$) to the final model<br>▪ QoL for people with dementia was better in couples than in adult-child relationships.<br>▪ Subgroups with female informal caregivers, living with male individuals with dementia in couples, reported the worst health among caregivers.<br>▪ The subgroup of older female informal caregivers in couples experienced the most severe burden on their physical and mental health.<br>▪ A model with six subgroups was the best fit for both studies. While the subgroups in both studies had similarities, significant differences were also observed. | ▪ Although substantive similarities between the class enumeration, class characteristics as well as associations with health care outcomes of both studies appeared, considerable differences are also evident.<br>▪ Replication study was partially limited, mainly due to variations structure and content of variables used (i.e., living situation, informal care relationship, paid work/occupation).<br>▪ In addition, variables (regarding regional care structures) that could be included in the German LCA were not accessible for the Netherlands.<br>▪ For future research, it would be conducive to use a basic set of sociodemographic indicators that is generally accepted, so that individual findings can be replicated more accurately. |

# 6. Discussion

The following chapter begins with a discussion of the main results, integrating the conceptual background. This is followed by a discussion of the methodological approach of the thesis. Both the systematic review (Wiegelmann et al., 2021a) as well as the original LCA with DemNet-D data (Wiegelmann et al., 2021b) and replication LCA (Wiegelmann et al., 2023) are discussed. However, some aspects that have already been discussed in the individual papers are left out. If necessary, these are only summarised briefly. A discussion of the methodological approach follows, and the discussion concludes with a presentation of the study's strengths and limitations, as well as the knowledge it has gained.

## 6.1. Discussion of findings

In three individual studies, the present study investigates a) the effectiveness and target group orientation of previous psychosocial interventions for informal caregivers in home-based dementia care dyads and b) whether valid types of home-based dementia care dyads can be described in a model-based manner by means of latent class analyses and whether there are differences between these groups with regard to health-relevant outcomes and c) whether this typology of dyads can be replicated in a further study.

The number of people living with dementia is expected to keep growing, and a pharmaceutical therapy with striking effect is not in sight, despite considerable financial investment (Livingston et al., 2020). At the same time, many people with dementia and informal caregivers wish to live in their own homes for as long as possible. This is also a political imperative due to the high-cost pressure in the health and care sector. Against this briefly sketched scenario, it is crucial to better tailor psychosocial interventions to informal dementia caregivers as individuals in heterogenous dementia care dyads. Firstly, to be able to strengthen psychosocial health more effectively. Secondly, to more efficiently direct scarce resources to specific needs of certain target groups, instead of further promoting more standardised support structures that have a poor fitting with people's lives. The following subsections describe and contextualise the key findings of this thesis.

### 6.1.1. Findings regarding psychosocial interventions for dementia caregivers

The adverse health outcomes associated with informal dementia caregiving have been demonstrated in a multitude of studies. To reduce negative health effects, there is need for a robust and comprehensive knowledge base on health promotion interventions and their effects on relevant dimensions of psychosocial and mental health, such as burden, well-being, depression, or quality of life. The first sub-theme addressed in this cumulative dissertation was, therefore, the question of the effectiveness and target group orientation of previous psychosocial interventions for informal caregivers in home-based dementia care dyads. These questions were examined on the basis of a systematic review.

When the main results of the first sub-study are reflected upon once again, it becomes visible that a large number of different interventions could be identified in the international literature. The intervention programmes differ in terms of their basic content, the target group, the intensity of the intervention (dosage), and the type of delivery. In addition to the diversity of psychosocial intervention programmes, the studies of parallel interventions also vary, sometimes considerably. Here, differences can be found in the size of intervention groups and control groups, the follow-up concepts and/or their time intervals, as well as the outcome measurement instruments used. All in all, this is a rather heterogeneous landscape of intervention programmes. In this respect, the sub-study confirms older studies (Abrahams et al., 2018; Gaugler et al., 2017; van't Leven et al., 2013). However, it cannot be concluded from the diversity of intervention programmes and study designs that certain subgroups of informal dementia caregivers have also been conceptually addressed with tailored programmes to suit their specific life and care situation. This is only partially the case in a few programmes (more on this below).

Regarding the effects of intervention programmes investigated, results are mixed but with some promising findings. There are positive effects of psychosocial interventions on mental health outcomes. However, only in one-third of the included outcomes and more likely when outcomes were measured directly after the intervention (pre-post design). The outcome "subjective burden of care" showed most frequently reported positive effects, with the intervention type “leisure time and physical activity” as most successful in reducing subjective caregiver burden. This confirms results in previous studies (Orgeta et al., 2014). As described in other studies, psychoeducational programmes also show promising results with regard to subjective caregiver burden (Pinquart/Sörensen, 2006; Martin-Carrasco et al., 2014). Regarding the outcome depressive symptoms, based on this study, the best intervention type is “cognitive behavioural interventions”, as also mentioned by Gallagher-Thompson and Coon (Gallagher-Thompson/Coon, 2007). Furthermore, psychoeducational programmes are also relatively successful in terms of reducing or stabilising anxiety. One main implication emerges from the results regarding effects. It might be crucial to adapt certain interventions to certain health outcomes, e.g., leisure and physical activities to reduce care burden or implement cognitive behavioural interventions to improve depression.

The first sub-study illustrates that only a small number of studies are conceptually designed to target specific subgroups of dementia dyads. Despite this, these few " tailored" approaches show hardly any positive effects on the mental health of family carers. At first glance, this seems to contradict the argument that a more targeted approach leads to improved health outcomes. However, based on the analyses carried out here, it is reasonable that although the rationale for subgroup orientation is stressed by authors, the reported practical adaptation of interventions to meet specific subgroup needs seems inadequately implemented. Hence, this review points out that it is crucial to carry out a detailed analysis of the heterogeneity of the target population prior to the design of an intervention. Analysing heterogeneity should then be a key element in all phases of intervention development, implementation, and evaluation (mainstreaming heterogeneity).

From a methodical point of view, there is still room for improved intervention study design, for instance with regard to larger population samples and the implementation of long-term follow-ups that take place at least 6 months after the end of the intervention, regarded as a minimum interval to study lasting effects of interventions.

### 6.1.2. Findings regarding subgroups of home-based dementia care dyads

This research illustrates the existence of meaningful subgroups within dyadic dementia care constellations across two datasets that share structural similarities but differ in content (Wiegelmann et al., 2021b; Wiegelmann et al., 2023). In both sets, these subgroups can be discerned through a common set of indicator variables, including the age of the person with dementia, age of the informal caregiver, sex of the person with dementia, sex of the informal caregiver, informal care relationship, living situation, and occupation of the informal caregiver (ibid.). In both investigations, a 6-class model emerged as the most suitable. This outcome is expected, considering the structural resemblance between the datasets, for instance, the general size of the datasets and the fundamental similarity of key indicators used to define classes, as indicated by statistical metrics (BIC, LRT, Entropy) and interpretability. Despite sharing the same number of classes, significant differences persist in terms of class sizes, class characteristics, and associations with health-related outcomes. These distinctions arise from the heterogeneity between the two datasets and populations under study (ibid.).

A key aim of the sub-studies 2 and 3 was to draw conclusions about specific groups "at risk" by analysing the associations between the identified dyad subgroups and the applied health care-related outcomes. The potential for identifying specific subgroups at risk (or, on the other hand, groups that are particularly resilient to stress) is emphasised in a recently published attempt to establish an innovative research framework for psychosocial dementia research (Gaugler et al., 2019). Identifying specific risk groups based on sociodemographic factors is crucial for targeted prevention and intervention, addressing healthcare inequalities, optimizing resource allocation, early detection of health risks, tailoring health communication, upholding ethical principles, and fostering research for a deeper understanding and development of effective health strategies (WHO, 2009). Socio-demographic characteristics may indicate specific risk factors or needs within dementia care dyads. By identifying such characteristics, early identification and preventive strategies can be developed to address potential problems before they become more acute. Cautious conclusions about two specific risk subgroups can be drawn from a summary of sub-studies 2 and 3 (Wiegelmann et al., 2021b; Wiegelmann et al., 2023).

The first potential risk group is that of older female carers in couple dyads. These caregivers are part of older couple dyads living together. Health outcome scores are worst in those dyads in both of the samples examined. A result that confirms findings from previous studies (Pinquart/Sörensen, 2011; Potier et al., 2018). The reasons given for the worse health condition of these informal dementia caregivers are, on the one hand, the intensity and closeness of the care situation and, on the other hand, their own advanced age, which is associated with an increased risk of developing medical issues for themselves (ibid.). Useful intervention programmes in this context might involve providing opportunities for respite through services like, for instance, day care, short-term care, or respite care, and offering activities that contribute to individual health promotion (e.g., to improve cardiovascular health, maintain mobility and strength, provide opportunities for social interaction) such as programs focused on physical activity or leisure activities in group settings.

The second subgroup emphasized here as potentially vulnerable in both LCAs is the group of dyads with working caregivers. Although the instruments used are conceptually different, it is interesting that the class with the most unstable arrangement in the German sample is simultaneously the one with the most unmet needs in the Dutch sample. At the same time, the family carers in this dyad subgroup report a relatively good state of health. For this subgroup, the focus should thus be on maintaining a good state of health (primary prevention). Early preventive services (information and counselling to prevent health problems) to ensure mental, physical, and social health are suitable for accompanying these dyadic care relationships. As the family carers in this type of dyad are typically employed, it is important to address issues of reconciling care and work more intensively and to take into account both the restrictions and the resources resulting from employment when designing care arrangements (Atienza et al., 2000). Possibilities for involving employers in the design of care planning focused on the work-care balance should also be examined, e.g., through programmes aimed at flexible working time models or through workplace health promotion programmes (Wang et al., 2011). As the extensive amount of care work, especially for women carers, may lead to a reduction in working hours or to giving up paid work, the potentially negative effects on income and retirement income must also be taken into account in counselling contexts (Knauthe/Deindl, 2019). The two examples show the added value of identifying socio-demographic subgroups of informal dementia care dyads when it comes to developing tailored support services for informal caregivers.

There are two broader conceptual ideas that should be taken up at this point. Both are interlinked but have different perspectives. First, the added value of a typological approach over an individualistic approach. Second, the strength of bringing in the social context by focusing on the investigation of different dyadic environments of informal caregivers of people with dementia. The development of typologies centres around the grouping of empirical cases on the basis of conceptually grounded characteristics used for classification, with the aim of achieving a high degree of homogeneity within a type and significant heterogeneity between types (Schönig, 2019). Typologies refer to the concept of the 'limited individuality' of individuals and their integration into social contexts. The identification of typical elements (patterns) within individual cases provides an opportunity for a more detailed understanding of characteristic and specific features. The knowledge gained in this thesis by developing dyad typologies consists of analysing the social structures in which individual informal caregiver find themselves (in this case: dyadic relationship constellations) and then to be able to derive more precise intervention strategies for health promotion on this basis. People with dementia and their caregivers have an intense relationship with each other. The needs, challenges, and resources of one person can, therefore, be strongly influenced by the situation of the other. A typology that takes into account both members of the dyad can better capture this form of interdependence between the two individuals than focusing only on the individual. The added value or knowledge gained from typologies for care practice may lie in the identification of different target groups with different demands on service providers and care services, as well as different circumstances and motivations that lead to a likelihood of using and benefiting from, for example, different counselling, support, prevention, and health promotion services (van Mierlo et al., 2012). Overall, the typological approach developed in this thesis offers the potential to consider multiple dyadic contexts of home care situations in dementia. The deduction of care approaches could, therefore, aim to provide a flexible and differentiated range of services tailored to the specific characteristics of the subgroups (Dreyer et al., 2022). This could lead to improved quality of care and increased satisfaction of the persons concerned.

The LCAs in sub-studies 2 and 3 are contributing to the research into the various social contexts in which informal caregivers of people with dementia are involved (Wiegelmann et al., 2021b; Wiegelmann et al., 2023). In this context, the dyadic relationship is understood as the smallest social context possible (Simmel, 1902). We know from research that social contexts influence how individuals act with regard to their health and that health outcomes are to a certain extent also determined by social factors (Berkman et al., 2000; Thorlindsson, 2011). An individualised view of informal caregivers therefore falls short. Depending on which social context factors characterise the dyadic situation, support services adapted to the specific situation are required. An individualised perspective on informal caregivers could potentially overlook opportunities and constraints influenced by specific dyadic situations, for instance, counselling scenarios, interpreting the individual caregiver's behaviour as a result of personal actions rather than as a product of their particular circumstances (ibid.). The typologies of dyads, as developed in the sub studies 2 and 3, contribute to overcome the relatively strong focus on the individual in health care research. First, informal caregivers are understood as individuals acting in a dyadic environment. Second, they are considered in a differentiated way in relation to different typical dyadic environments that influence their situation and their needs for support (Wiegelmann et al., 2021b; Wiegelmann et al., 2023). This abstracting and systematising helps to enrich the individual perspective with a structuralist perspective. The gain in knowledge lies in making the dyadic social relationship constellation in which family caregivers of persons living with dementia find themselves more visible and, subsequently, in being able to derive more appropriate intervention strategies on this basis. Typologies provide interpretative tools for analysing individual cases. Types bridge the complexity of the individual case and the tendency to draw uninformative generalisations based on population averages (Schönig, 2019). By allowing individual cases to be assigned to a type, they can help to identify more precisely the characteristic and specific features that are relevant to health care behaviour and related interventional support programmes.

### 6.1.3. Findings regarding the replication of the dyad typology

Replication studies operate on the basic principle that scientific knowledge shouldn't rely on random chance. Instead, it should be systematically and transparently built over time through multiple studies, producing results applicable to at least some current or future target populations of interest (Steiner et al., 2019). A replication study is considered successful when it reproduces the key findings of the original study with a similar degree of precision and consistency. Success in replication can be characterised on the basis of proven statistical comparative parameters or using narrative or qualitative criteria (ibid.). One limitation of the present study can thus be seen in the fact that the comparison of the two LCAs was carried out on a narrative or qualitative level. As already mentioned, this replication study (sub-study 3 of the dissertation) can only be described as partially successful. It has both successful and unsuccessful components due to the variations between both original studies used for both LCAs (MacNeil Vroomen et al., 2012; Wolf-Ostermann et al., 2017; Laporte-Uribe et al., 2017). Although the indicators relevant to the formation of the classes are largely similarly distributed, there are also some significant differences between the two samples. This means, for example, that two classes with male carers are identified in the LCA with the Dutch data. Furthermore, class-forming indicators differ in the way they were collected, and health care-related outcomes also largely differ between the two LCAs. Nevertheless, it can be concluded that the replication study followed a rigorous methodical approach, reports transparently on the statistical procedure, contributes to the knowledge about dementia care dyads, and addressed limitations of the analysis conducted. These aspects allow the LC analyses presented here to be tested on the basis of different populations in future research. Future replication studies could be optimised through the use of consented core indicator sets for both class-building procedure and association with distal outcomes of interest. This harmonisation of data across studies could help to improve the evidence base and thus also lead to more efficient support services for the target groups under investigation.

## 6.2. Discussion of the methodical approach

The way research questions are answered is critical in a thesis. This is why the methodological approach is so important. It ensures that others can reproduce the procedures, and that your methods can be criticised and validated by others. A clear methodology strengthens the entire work's credibility and quality and guarantees the reliability of conclusions (Diaz-Bone/Weischer, 2015).

### 6.2.1. Systematic review

Overall, systematic review approach proved appropriate for identifying effective interventions to strengthen the mental health of informal caregivers in dementia care dyads and for examining the subgroup orientation of intervention programs. To ensure the methodological quality of the review, we applied several scientific standards. Thus, the PRISMA guidelines were used to ensure transparency, accuracy, and completeness of reporting on the review process and results (Page et al., 2021). Furthermore, to improve the objectivity, reliability, and quality, screening and selection of studies were performed with two independent reviewers, and their sufficient agreement was determined using the Cohen coefficient. Likewise, the methodological quality of the studies was assessed using a tool based on Cochrane Collaboration Guidelines. Only studies that scored at least 8 out of 11 points ("high methodical quality") based on the criteria of the tool were finally included. Yet, the overall methodological quality of the review could have been improved if a) a review protocol had been prepared in advance and published, e.g., via PROSPERO, and b) a more established instrument had been used to assess methodological quality and risk of bias.

### 6.2.2. Latent class analysis (LCA)

LCA showed to be a suitable approach to identify dyad subgroups within both the DemNet-D and the COMPAS population. Of course, we know from the literature that informal caregivers and persons with dementia differ in terms of socio-demographic and relational aspects. But in most studies, these aspects are either considered in isolation or are loosely presented side by side as individual factors influencing a phenomenon under investigation. However, this does not provide a comprehensive understanding of dyadic constellations, whose central characteristic is multidimensionality. This is where LCA comes in, and as a multidimensional and model-based method, it is particularly suitable for uncovering hidden groups dyads similar with respect to sociodemographic and relational factors. Nevertheless, LCA also has its pitfalls, which are inherent in the method. Perhaps the most important aspect to mention here is that LCA is a data-driven process. The problem with a purely data-driven approach is that it may detect random or insignificant patterns. By relying solely on the data, you might fall for "bogus patterns". Such patterns are unstable and non-reproducible and cannot be found in other datasets. This results in misleading conclusions, making it challenging to draw reliable conclusions. Therefore, it is crucial to consider not only the data but also the conceptual and practical knowledge when identifying groups or patterns. A well-balanced approach that incorporates both the context and data can effectively differentiate substantial and meaningful patterns from random or insignificant ones.

In this thesis, it has been decided to respond to these challenges on the one hand by selecting, as class-forming indicators, those that have already been described in the literature as central indicators. Furthermore, the replication study is also a method to reduce the problem of being driven by data. The differences in the results between sub-studies 2 and 3 are indeed a result of the data-driven nature of LCAs. It is, therefore, important to conduct replication studies to uncover and discuss this. In the future, it would, therefore, be important to have larger datasets with the same socio-demographic and relational data available to alleviate the challenges of data-drivenness.

It is important to emphasize that no causal relationships between the identified classes and the relevant health care-related outcomes can be derived from the 3-step LCA carried out here. This analysis technique aims to examine associations and patterns between the latent classes and the distal outcomes. Although it allows us to understand and describe the relationship between the classes and the distal outcomes, it does not allow any direct conclusions regarding causal influences. It is important to keep this in mind when interpreting the results, as the analysis is only based on associations and does not show direct causal relationships.

Some other methodical factors limited the findings of the latent class analyses conducted. Both datasets, DemNet-D as well as COMPAS, are not random samples and therefore have some limitations with regard to the statistical generalisability. Furthermore, since we conducted secondary analyses, we had to deal with restrictions due to the original data, (i.e., self-assessment measures, sophistication of variables). As we used only cross-sectional data in both LCAs, future research should add a longitudinal perspective; i.e., using a Latent Transition Analysis (LTA) to examine if and how dyads move from one latent class to another as time progresses and to see if this has an impact on health care-related outcomes.

### 6.2.3. Replication approach

The way a replication was carried out in the third sub-study can be characterised as a direct or exact replication study (Steiner et al., 2019). This is a type of research where investigators try to reproduce as closely as possible the methods, procedures, and conditions of a previous study to see if they can get consistent or identical results. This type of replication helps assess the reliability and generalisability of the original results and contributes to the robustness of scientific knowledge (ibid.).

A favourable starting point for replication was that the datasets were quite similar in structure and also of comparable size. Furthermore, LCAs are generally relatively well-suited for replication studies, which is partly due to the clearly defined method, the standardised software, the robustness of the method, and a clear focus on the identification of classes and—if it’s a Step3 approach—their associations with distal outcomes. The criticism of LCA as a somewhat subjective approach could be addressed in this study by the effort to replicate the original LCA with a different sample to prove whether the results of the first study were reliable. The main limitations of this replication have already been mentioned and refer to methodological differences between the DemNet-D and COMPAS datasets. This is due to variations in instruments used to collect data in both studies (variables like living situation, informal care relationship, paid work/occupation). Additionally, single variables (regarding regional care structures) that could be included in the original LCA were not available for the replication study. For future research, it would be important to replicate latent class structures with data from different countries and world regions with different health and care systems to verify the general validity.

### 6.3. Strengths

This thesis explores an innovative field of research that focuses on people with dementia and their informal caregivers in typical dyadic constellations, taking a broad view of their living and care contexts, located in domestic settings. This is particularly relevant due to the expected increase in the number of very old people in the population and a related increased likelihood of an overall rise in the number of people with dementia. The thesis thus makes an important contribution with regard to existing research gaps.

The combination of the methodological approaches (conducting a systematic review, carrying out latent class analyses, conducting a replication study) enabled a comprehensive, literature-based, as well as an empirical research-based, elaboration of significant aspects related to dyadic constellations in home care arrangements in dementia. The focus on subgroup analysis extends through all three individual papers. In addition, to the best of the author's knowledge, the multidimensional and model-based consideration of typical subgroups of dementia dyads via latent class analyses breaks new ground and was also conducted for the first time in the context of a cross-national replication study between structurally similar datasets from Germany (DemNet-D study) and the Netherlands (COMPAS study).

A number of challenges have led to the scarcity of replication studies up to now, even though they can significantly contribute to research rigor and reliability. This study has explored the field of replication research and aimed to highlight its potentials and challenges in a transparent way. In order to stimulate additional replication studies within psychosocial dementia research, it is important to change the incentives and encourage the conduct of replication studies to increase the overall quality of scientific evidence.

### 6.4. Limitations

Although the presented thesis has a wide approach, certain aspects were not taken into consideration. Further research on informal dementia care dyads should add relational indicators, such as relationship quality, relationship closeness or positive and negative dyadic interactions, as those indicators depict important dynamic features of dyad constellation, relevant for e.g., coping behaviours that in turn moderate health related outcomes. As we used only cross-sectional data in both LCA studies, future research should add longitudinal perspectives; i.e., to analyse changes over time in relevant health related outcomes within different dyad subgroups or even changes of dyadic constellations over time. Another limitation was the use of secondary data in the latent class analyses. This sets limits both in the selection of indicators, the harmonisation of indicators, and the evaluation and interpretation of results. Although dyads are the focus of interest in this thesis, conceptually the focus of consideration is on informal caregivers as actors in home-based dementia care dyads. Further research should also focus more on the situation of persons living with dementia and consider both dyadic actors equally.

### 6.5. Gain in knowledge

Based on a broad systematic review of the literature, it could be shown that only a very small number of intervention studies focus on health promotion of specific subgroups of informal caregivers within dementia dyads and if they do so, they operate unidimensional, e.g., differentiate with regard to gender or urban/rural residence. In the context of both latent class analysis, it has been shown that typical dyadic subgroups can be modelled multidimensionally along sociodemographic indicators and that relevant parameters of the psychosocial health differ between these subgroups. From a methodological point of view, it was possible to show potentials and pitfalls of a replication approach. It has been shown that it is crucial to invest considerable time in harmonising data sets in order to arrive at comparable results in replication studies. If this succeeds and—as shown in the context of the present thesis—very similar and structurally similar classes could be identified in different populations, the potential of replication studies becomes apparent. But this is precisely where the major challenges lie in methodically replicating an original LCA using a second dataset. If two datasets are too heterogeneous, i.e., if too many different measures were used, harmonisation reaches its limits and the results in a second study are consequently different from those in the first investigation.

This is also a key reason why the replication of the class structure in this thesis was only partially successful. It is also difficult to compare outcomes across two studies if—although conceptually similar—different measures were used. Here, too, full replication is impossible and only cautious comparative approximations at the conceptual level are reasonable. Nevertheless, with due caution, it can be concluded on the basis of the results of this study that psychosocial health risk profiles of informal dementia caregivers differ depending on the dyadic constellation in which they are situated. These specific profiles need to be considered more precisely in the context of the tailoring of support structures.

## 7. Implication for future research, practice and policy

The following implications for the fields of research, practice, and policy can be derived from the findings of the three single publications (Wiegelmann et al., 2021a; Wiegelmann et al., 2021b; Wiegelmann et al., 2023).

### 7.1. Implications for research

For now, there is no evidence for a medical cure for dementia. This emphasises the urgent need to intensify research efforts on the psychosocial health of both individuals of the dyad, the informal caregivers and the person living with dementia.

Research on target group orientation: The results of this thesis indicate the need to develop tailored strategies to approach dyad subgroups specifically in terms of health-related counselling, service use promotion, and easing of caregiver burden. In addition, a range of research indicates why target group approaches should be given a higher priority in research. Examples to be mentioned here include variation in needs, preferences, social circumstances, and cultural backgrounds. A targeted approach makes it possible to address this diversity and better understand specific needs (Campbell/Quintiliani, 2006). Furthermore, by targeting specific groups, resources might be used more efficiently, as they can be focused on those aspects that are most relevant to the specific target group (Lustria et al., 2013; Bol et al., 2020). A third aspect is that measures tailored to the specific needs and challenges of subgroups are more likely to be effective and more efficient. Targeted support can therefore help achieve better outcomes in terms of quality of life, psychosocial well-being, and disease management (ibid.). Another example is improving acceptability. Interventions that are tailored to the specific needs and preferences of subgroups are likely to be better accepted. This encourages active participation in treatment and support programmes and may increase willingness to seek help (Beck et al. 2010). More targeted research is needed on these topics to supplement evidence based on person-centred and population-based approaches.

Research on dyadic constellations: The underlying data of this thesis does not allow conclusions on the social dynamics and interactions of dementia care dyads. However, recent studies indicate that aspects of relationship quality are a promising factor in reducing informal caregiver distress and improving carer resilience (Leung et al., 2023). Further research could combine exploring structural aspects of dyadic constellations with indicators of relationship quality in informal dementia care. This would provide a more comprehensive picture of dyadic situations and insights into whether and how dynamics and interactions differ in typical dyadic constellations.

Replication studies: This study underlines the importance of replication studies, both in terms of their potential and their pitfalls. As already explained, replication studies might be associated with a number of challenges (e.g., differences of methods or samples). However, it would be valuable if more replication studies were conducted to foster reliability, replicability, and validity of research findings and to strengthen the basis for evidence-based practices and decision-making in this area. To strengthen replication studies of dyadic constellations in dementia, it would be helpful if a core set of sociodemographic indicators would be developed. Such a set would significantly improve the comparability of studies and, therefore, the opportunity for replication of research findings.

This research provides some initial pointers, albeit, of course, with limitations considering the complexity of dyadic arrangements. Here it would be important to provide more support for innovative research projects.

### 7.2. Implications for practice

Informal caregivers of individuals living with dementia are considered a vulnerable group that needs to be supported in a focused and targeted manner, embedded within local structures. For example, to compensate for care-related health problems and to promote social participation (Brodaty/Donkin, 2009; Gaugler et al., 2019). The implementation of support services is the domain of practitioners, e.g., in therapeutic, nursing, or counselling programs. The results of the thesis offer some indications of possibilities for further development. With regard to the practice of care counselling, the results of the present study can contribute to inform care counsellors about specific dyadic constellations in home care with dementia and certain related issues. This information can then be integrated into structures and processes of current person-centred counselling routines by the actors of the counselling practice. For example, dyadic constellations and care needs might be assessed, adapted and addressed on a regular basis as part of a regional individualised manner through case and care management. For the further development of target group-specific preventive measures to strengthen health, different stakeholders should be involved depending on the dyad type. For example, employers should be involved when it comes to working caregivers, or there should be more cooperation between local authorities in distance caregiving situations.

The present study takes up the concept of target group orientation of health promotion and illustrates that: a) there are different dyadic constellations in home care in dementia and b) on the basis of these differences, it can be outlined that certain support services can be useful for certain dyad subgroups in a preventive-relieving way. Stakeholders in the care and health professions who practice/provide or inform/advise on specific interventions can use the results of the study to identify target-group-specific subgroups of informal caregivers of persons living with dementia who might particularly benefit from these interventions. The results may be of additional benefit in pre-identifying the most feasible support services needed for informal caregiver in specific dyadic subgroup constellations and in providing improved tailored interventions for clients. Moreover, the findings can be used alongside other informational materials and an individualised assessment to justify the selection of specific preventive-relieving interventions. In a specific case, using the results may draw attention to the absence of a potentially effective intervention in a region where dyads live, and thus provide an incentive to implement appropriate interventions for main dyad subgroups regionally. Based on the profiling approach by Dekkers et al. (2018) the process of tailoring support for informal caregivers within certain dementia care dyad constellations may use a stepwise approach (Figure 3 next page) that involves several key stages.

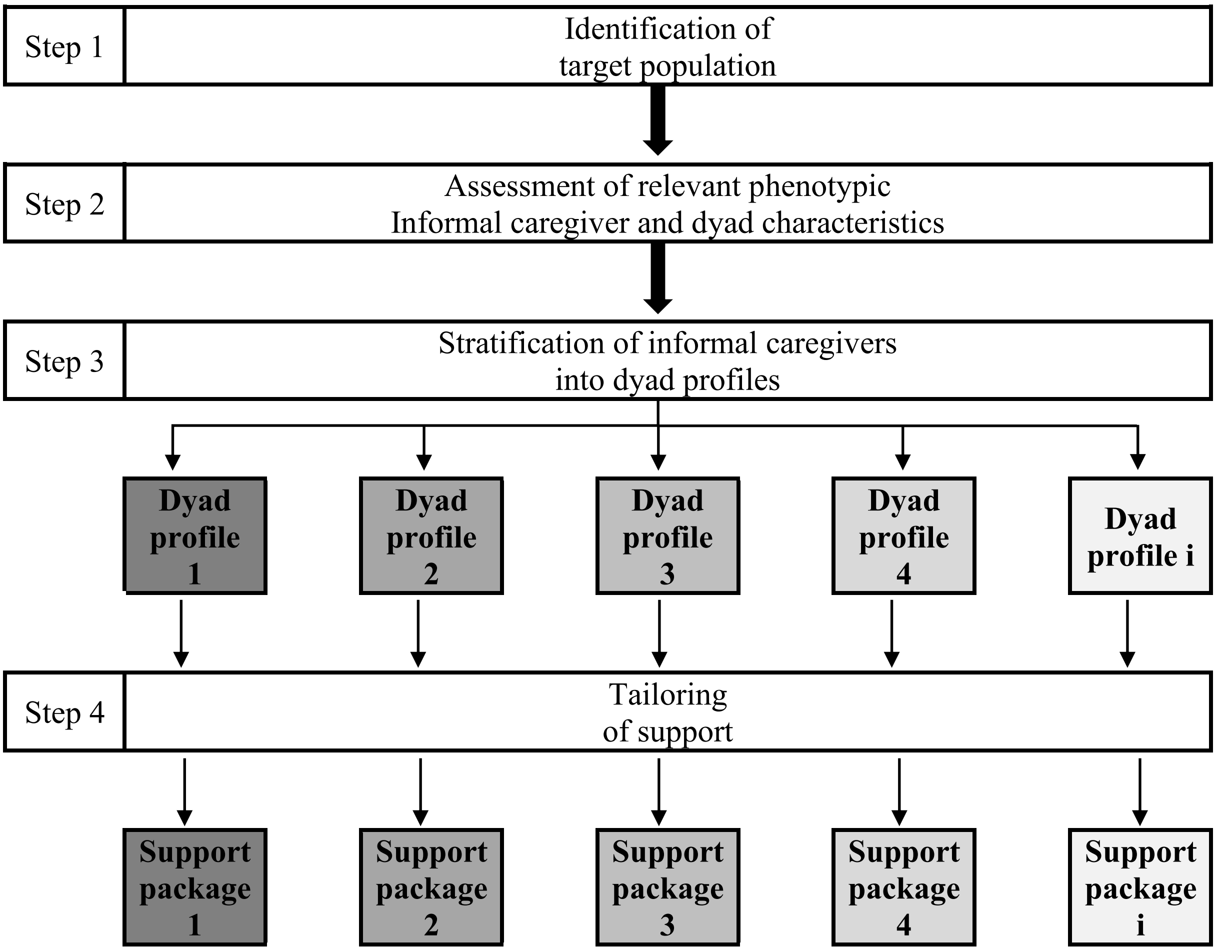

*Figure 3 The dyad profiling approach.*

1) Identification of the target group: The initial phase involves identifying the specific group of interest, which in this case comprises informal caregivers involved in dementia care dyads. This identification allows for a focused and relevant application of the tailoring approach.
2) Assessment of informal dementia caregiver and dyad characteristics**:** Support providers undertake a thorough assessment of various characteristics associated with informal caregivers and dyad characteristics. These could include sociodemographic and relational factors but also other relevant psychosocial aspects such as coping strategies and outcomes like quality of life, health status, caregiver stress, etc.
3) Stratification of informal dementia caregivers: Caregivers are classified into distinct dementia dyad profiles or subgroups based on the indicators of the assessment. This categorisation aims to create more homogeneous groups in terms of support needs. Although the diversity within these subgroups is acknowledged, the stratification facilitates more tailored and effective interventions.
4) Tailoring support for informal dementia caregivers: The final step involves tailoring the support provided to each subgroup based on the identified profile. Care interventions,

resources, and support mechanisms can be adapted to address the specific needs of informal dementia caregivers within each dyad subgroup. This tailored approach acknowledges the unique challenges and requirements resulting from providing informal care in different dyadic environments, which may contribute to enhance the effectiveness and impact of the support provided. Support packages may differ in content, dosage, type of delivery etc.

The identification of typical dyadic constellations as well as the analysis of subgroup-specific health outcomes, is not a substitute for a professional counselling approach. Rather, such approaches may provide evidence-based background information (for instance as a focused factsheet) on specific dementia care dyad constellations and the life and care situations that typically arise from them beyond the individual case. This well-founded information can be used in a purposeful manner in individualized counselling processes. Pfeiffer et al. (2017) also emphasize that the resources of long-term care counselling centres should always be kept in mind. It is always important to ask how much additional background material (screening, intervention factsheets, etc.) can be used effectively in practice and whether, for example, additional screening can be a way to use any personnel and time resources more effectively. In any case, it is important to involve the counsellors, to train them and to know their previous experience, training backgrounds, etc. in detail (ibid.).

## 7.3. Implications for policy

Regarding policy regulations, there is a pressing need to establish legal conditions to expand funding and support for dyadic-based support structures and intervention studies. Particularly those approaches aimed at improving tailored support to strengthen the psychosocial well-being of informal caregivers within home-based dementia dyads. This would also address and strengthen the principle of ageing in place. Furthermore, a political effort would be welcome which paves the way for improving tailored counselling practices at a regional or local level. Additionally, it is advisable to promote the integration of tailored dyadic-focused approaches into the broader fields of nursing, therapy, and psychosocial practice. This also requires financial resources for specific training and professional education for staff in care and nursing services for people with dementia and counselling agencies.

The results of this thesis highlight the potential value of replication studies in assessing the robustness of research findings. To bolster the evidence base, it is essential to encourage more frequent comparisons of research results across diverse populations. This can be achieved by dedicating future research funding to projects that seek to establish a core dataset for harmonising sociodemographic, relational and contextual data of dyads, thus facilitating easier replication of individual study results. Moreover, promoting the exchange of data among research projects and supporting large-scale, long-term studies with publicly accessible datasets can aid in the comparison of study findings. This is particularly vital for subgroup analyses and subsequent tailored recommendations, as intervention studies with a control group design often have small sample sizes.

Looking forward, several avenues for future research and action emerge. Firstly, there is potential for expanding research funding with a pointed focus on identifying specific target groups. This exploration could apply milieu-specific typologies, such as the SINUS-Milieus derived from market research, to gain more profound insights into dyadic constellations, relationship quality as well as coping strategies (SINUS 2021). The SINUS Milieus approach offers a more precise classification of target groups beyond conventional sociodemographic characteristics. It posits that to effectively engage with individuals or target groups, it is crucial to intimately understand their emotional states, inclinations, values, life goals, lifestyles, and attitudes. It is advisable to assess the applicability of these approaches for psychosocial dementia intervention research and consider testing them through pilot projects (ibid.). Moreover, there is a strong reason to support large-scale, multimodal intervention studies that focuses on the psychosocial well-being of informal caregivers in dementia care dyads. Based on the present study, it can also be concluded that it might be beneficial to combine the approach of increased target group identification and analysis with the use of multimodal interventions focusing on social, psychological, and physical support. The dyadic profiling approach (Figure 3), based on the work of Dekker and colleagues (2018), might be a suitable starting point for this.

## 8. Conclusion and outlook

In light of extensive literature, secondary data analyses and conceptual underpinning, the present study contributes to important strands of discourse in the field of psychosocial dementia caregiving research as follows. The study emphasises the importance of the psychosocial health of informal carers of people with dementia. This is relevant in the context that there is currently no medical cure for dementia, and that it is of key importance to identify caregivers at risk of the declining capability to "live well" (Clare et al., 2022). Despite the knowledge of the importance of promoting the psychosocial health of informal carers, relatively little progress has been made in this area to date. This paper argues that psychosocial support services should be tailored to specific dyadic constellations and developed in a circular development process that is as participatory as possible.

Furthermore, the study strongly suggests that it is relevant to consider family carers in the context of their respective dyadic relationship constellation with the person with dementia, as it is evident that different needs can develop from different constellations. The distinct roles that family caregivers of people with dementia play in these diverse dyadic relationship configurations can result in different sources of stress and support needs. Looking at these relationships in a differentiated way can help create support and solutions that meet the needs and challenges of family caregivers. Future research should continue to take a contextual approach and broaden the classical focus on dyads to whole informal support networks including family, friends, colleagues, and neighbours (Hochgraeber et al., 2023). Especially regarding domains of social health of informal caregivers (i.e., sizes of social networks, types of social support), widening the perspective in this way would be an important next step.

This thesis shows that dyadic relationship constellations can be comprehensively described using the three-dimensional idea of the social relationship (structure, function, appraisal). Future research should include the two dimensions of function and appraisal to be able to look more closely at dynamic factors, as the present study only focuses on the constellation/structure of the dyadic relationship. This study couldn't consider these perspectives.

In essence, there is a need to strengthen the focus on dyadic target groups or subgroups to better tailor support services, while also reinforcing the identification of target groups through a multifaceted perspective and approach. It seems worthwhile to further explore the application of latent class analysis in cross-sectional and longitudinal analyses as a quantitative method for identifying typical subgroups within heterogeneous populations. To facilitate a more dynamic examination of subgroups, the utilisation of latent transition analysis may provide additional benefits in analysing typical changes over time.

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# Appendix

## Appendix I

1. Publication: Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review

Note: Appendix I is not included in the publication of this dissertation. The published article is available at the following link:

doi:10.1186/s12877-021-02020-4

## Appendix II

2. Publication: Sociodemographic aspects and health care-related outcomes: a latent class analysis of informal dementia care dyads

Note: Appendix II is not included in the publication of this dissertation. The published article is available at the following link:

doi:10.1186/s12877-021-02020-4

## Appendix III

3. Publication: Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads: A latent class replication study

Note: Appendix III is not included in the publication of this dissertation. The published article is available at the following link:

doi:10.1186/s12913-021-06708-6

## Appendix IV: Declaration on the contribution to the individual studies in joint authorship

The authors of the individual papers for this dissertation adhere to the guidelines recommended by McNutt and colleagues (McNutt et al. 2018). According to the criteria, the authors are expected to make significant contributions to either:

- Concept of the work or
- Layout of the paper or
- Data acquisition/data analysis or
- Interpretation of the data or
- Development of new software used in the work or
- Draft or substantial revision of the work

Furthermore, the entire author team must have approved the submitted version (and any substantially revised version that includes the author's contribution to the study) and agreed both to be personally responsible for the author's own contributions and to ensure that issues regarding the accuracy or completeness of the submitted version are settled. The proposed standards were based on the statement of the International Committee of Medical Journal Editors, which is widely used in medical journals. This statement was generalized to encourage widespread use (McNutt et al., 2018).

Compliance with the standards and the contribution roles of each author can be seen in the following table.

*Table Contribution by authors of the individual papers according to CRediT (McNutt et al. 2018)*

| Author's name | Contributor roles based on CRediT (Contributor Roles Taxonomy) |
|---|---|
| **Study 1: Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review** | |
| Henrik Wiegelmann | Conceptualization (lead), Data curation, Formal analysis (lead), Investigation (lead), Methodology, Project administration, Writing – original draft (lead), Writing – review and editing (lead) |
| Sarah Speller (SaSp) | Formal analysis (supporting) |
| Lisa-Marie Verhaert (LMV) | Writing - review & editing (supporting) |
| Liane Schirra-Weirich (LSW) | Writing - review & editing (supporting) |

| | |
|---|---|
| Karin Wolf-Ostermann | Conceptualization (supporting), Funding acquisition, Investigation (supporting), Supervision, Writing – review & editing (supporting) |
| **Study 2: Sociodemographic aspects and health care-related outcomes: a latent class analysis of informal dementia care dyads** | |
| Henrik Wiegelmann | Conceptualization (lead), Data curation (equal), Formal analysis (equal), Investigation (lead), Methodology (equal), Project administration, Writing – original draft (lead), Writing – review and editing (lead) |
| Karin Wolf-Ostermann | Conceptualization (supporting), Funding acquisition, Investigation (supporting), Supervision, Writing – review & editing (supporting) |
| Werner Brannath | Formal analysis (supporting), Methodology (supporting), Writing - review & editing (supporting) |
| Farhad Arzideh | Data curation (equal), Formal analysis (equal), Methodology (equal), Writing - review & editing (supporting) |
| Jan Dreyer | Writing - review & editing (supporting) |
| Rene Thyrian | Writing - review & editing (supporting) |
| Liane Schirra-Weirich | Conceptualization (supporting), Writing - review & editing (supporting) |
| Lisa Verhaert | Writing - review & editing (supporting) |
| **Study 3: Sociodemographic structure and health care-related outcomes of community-dwelling dementia caregiving dyads: a latent class replication study** | |
| Henrik Wiegelmann | Conceptualization (lead), Data curation (lead), Formal analysis (lead), Investigation (lead), Methodology (lead), Project administration, Writing – original draft (lead), Writing – review and editing (lead) |
| Karin Wolf-Ostermann | Conceptualization (supporting), Investigation (supporting), Supervision, Writing – review & editing (supporting) |
| Niels Janssen | Conceptualization (supporting), Formal analysis (supporting), Writing - review & editing (supporting) |

| | |
|---|---|
| Hein van Hout | Data curation (supporting), Funding acquisition (lead), Writing – review & editing (supporting) |
| Janet L. MacNeil Vroomen | Funding acquisition (supporting), Writing – review & editing (supporting) |
| Farhad Arzideh | Formal analysis (supporting), Methodology (supporting) |

McNutt, M. K.; Bradford, M.; Drazen, J. M.; Hanson, B.; Howard, B.; Jamieson, K. H.; Kiermer, V.; Marcus, E.; Pope, B. K.; Schekman, R.; Swaminathan, S.; Stang, P. J.; Verma, I. M. (2018): Transparency in authors' contributions and responsibilities to promote integrity in scientific publication. Proceedings of the National Academy of Sciences USA, 115 (11) 2557-2560.

## Appendix V: Eidesstattliche Erklärung

Hiermit erkläre ich eidesstattlich, dass ich die Arbeit ohne unerlaubte fremde Hilfe angefertigt habe, keine anderen als die von mir angegebenen Quellen oder Hilfsmittel benutzt habe, die den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen als solche kenntlich gemacht habe und die zu Prüfungszwecken beigelegte elektronische Version der Dissertation identisch mit der abgegebenen gedruckten Version ist.

Köln, 10.01.2024 ____________________________