THE POSSIBILITIES AND LIMITATIONS OF TECHNOLOGY IN PROMOTING SOCIAL PARTICIPATION AND ENRICHING DYADIC RELATIONSHIPS IN DEMENTIA CAREGIVING

A Thesis Submitted to the Institute of Public Health and Nursing Research, Faculty 11 of Human and Health Sciences, University of Bremen, in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Public Health (Dr.P.H)

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Summary

With no existing cure for dementia today, increasing attention is being directed at living as well as possible with the disease. This ethos is central to the concept of social health, where social participation and maintenance of relationships are central aspects. Dementia affects not only the individual with the disease but also those who care for them, with the quality of the caregiving relationship influencing the well-being of both dyad members. Positive experiences in caregiving through enrichment and social participation are important supporters of relationship sustenance.
There is unexploited potential in technology to promote social health in dementia caregiving dyads, and an existing knowledge gap in how facilitated social interaction might support relationship sustenance. This lack of knowledge has been highlighted by the impacts of preventive measures in response to the SARS-CoV-19 pandemic.

This cumulative dissertation aims to explore the potential of technological solutions to support dyadic caregiving relationships through enrichment and social participation in the context of dementia. Based on a systematic literature review, a pilot case study, a cross-sectional study, a feasibility trial and a scoping review, this body of work shows that 1) social technology can promote positive social interaction in caregiving dyads through a multitude of mechanisms; 2) little training is provided in nursing homes for caregivers to ensure social participation among residents with dementia using technology, with ad hoc solutions implemented to help residents connect with their loved ones virtually; 3) the severity of the COVID-19 induced social isolation of community-dwelling caregiving dyads was related to pre-outbreak social connections and the use of social technology to maintain these; 4) a tablet-based activation system is a feasible tool to facilitate positive social interactions in community-dwelling caregiving dyads; and 5) psychosocial intervention components may contribute to enrichment of dyadic caregiving relationships. Barriers and facilitators to incorporating social technology in dementia caregiving were also identified. Limitations derive from limitations of the data, including small sample sizes, restricted participant characteristics available, and little existing literature on novel technologies to support social health in a dementia context. Furthermore, the empirical findings must be interpreted in the context of unprecedented circumstances, especially as this dissertation focuses on social participation and relationship sustenance during times of severe social isolation and fear of infection.

To facilitate the availability and accessibility of social technology to support participation in meaningful activities and enrichment of dementia caregiving relationships, the aforementioned limitations must be overcome as far as possible. This can be achieved by conducting large-scale randomised controlled trials using social technologies in dementia caregiving dyads, both in institutional and community settings. Barriers and facilitators identified in this body of work must be taken into consideration when designing such trials. Moreover, social health must be recognised on equal terms as the physical and mental health domains if technology to promote social health is to be implemented successfully.

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Tables

Abbreviations

AAC	Augmentative and Alternative Communication
ACE	Addenbrookes' Cognitive Examination
AD	Alzheimer's Disease
BPSD	Behavioural and Psychological Symptoms in Dementia
BSFC	Burden Scale for Family Caregiving
Carer-Qol-7D	Care-Related Quality of Life 7-dimension scale
CBI	Caregiver Burden Inventory
CBT	Cognitive Behavioural Therapy
CDT	Clock Drawing Test
CGA	Comprehensive Geriatric Assessment
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CMAI	Cohen Mansfield Agitation Inventory
CMAI-SF	Cohen Mansfield Agitation Inventory-Short Form
COS	Core Outcome Set
CSDD	Cornell Scale of Depression in Dementia
CST	Cognitive Stimulation Therapy
DCC	Day Care Centre
DGP	Deutsche Gesellschaft für Pflegewissenschaft e. V
DIKS	Dementia Information and Coordination Centre
DISTINCT	Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology
DEMQOL	Dementia Quality of Life Instrument
EPC	Enrichment Processes in Family Caregiving
ESR	Early-Stage Researcher
EWGPWD	European Working Group of People with Dementia
FAB	Frontal Assessment Battery; LTC: Long-term Care
FAST	Functional Assessment Staging Tool
FC	Formal Caregiver
G7 (G8)	The Group of Seven (Group of Eight)
IC	Informal Caregiver
ICH-GCP	International Conference on Harmonisation-Good Clinical Practice
INDUCT	Interdisciplinary Network for Dementia Using Current Technology
INTERDEM	Early detection and timely INTERvention in DEMentia
IPP	Institut für Public Health und Pflegeforschung
LSC-DIPH	Leibniz ScienceCampus Bremen Digital Public Health
LTC	Long-Term Care
MB	Multimedia Biographies
MCI	Mild Cognitive Impairment
MEDLINE	The online counterpart to MEDLARS (MEDical Literature Analysis and Retrieval System)
MMAT	Mixed-Methods Appraisal Tools
MMSE	Mini-Mental Stage-Examination
MSC-ITN	Marie Skłodowska-Curie Innovative Training Networks
MSPSS	Multidimensional Scale of Perceived Social Support
NH	Nursing Home

NPI	Neuropsychiatric Inventory
NPI-Q	Neuropsychiatric Inventory brief Questionnaire
OME	Observational Measurement of Engagement
PAI	Positive Affect Instrument
PCC	Population, Concept, and Context
PLWD	People Living with Dementia
PRISMA-ScR	Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews
PwD	People with Dementia
QCPR	Quality of Carer-Patient Relationship
QoL	Quality of Life
QoL-AD	Quality of Life in Alzheimer's Disease
QUALID	Quality of Life in Late-stage Dementia scale
RAID	Rating for Anxiety in Dementia
RCT	Randomised Controlled Trials
RS-14	14-item Resilience Scale
RUD-FOCA	Resource Utilisation in Dementia – Formal Care
SLUMS	Saint Louis University Mental Status Examination
TBA	Tinetti Balance Assessment
WHO	World Health Organization
WHO-5	World-Health-Organisation-Five Well-Being Index

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Few achievements are obtained without the help of others, and this dissertation is no exception. Over these past three years, I have been surrounded by people (mostly in spirit, as the COVID-19 pandemic certainly has been isolating) who have encouraged me and supported me in various ways. It is with deep gratitude and appreciation that I would like to acknowledge and thank those who have contributed to the success of this project.

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Chapter One. Introduction

This chapter provides a contextual background and key concepts relevant to this cumulative dissertation. Dementia is defined, and the impact of the condition on individuals and society as a whole is outlined and situated within the current developments in the discourse about dementia. Current knowledge about the potential of social technology in dementia caregiving is thereafter discussed, before the notion of dyadic relationships is presented. Finally, the organisation of this thesis is described before an overview of the individual papers encompassed in this cumulative dissertation is presented.

1.1. Dementia – what is it, and how is it affecting our society?

'Dementia' is not one specific disease but a collective term for a group of symptoms due to neurocognitive disease, severely affecting memory, behaviour, cognition and social ability [1]. The most common cause of dementia is Alzheimer's disease, accounting for approximately 60-70 % of cases [2], but vascular dementia, dementia with Lewy bodies and frontotemporal dementia are also common diseases under the umbrella term of 'dementia' [1]. Dementia significantly interferes with an individual's ability to perform daily activities [3] and is one of the major causes of disability and care dependency among older adults worldwide [4]. This can be overwhelming for both the people living with dementia (PLWD) as well as their caregivers and family members. Globally, there are approximately 50 million people living with dementia, a number estimated to triple by 2050 [3-5]. Hence, there is a tremendous cost associated with the care provision of PLWD, not only among paid care providers (i.e., formal caregiving) but also for unpaid caregivers (i.e., informal caregiving) such as family members and close friends [4-7].

The World Health Organization's (WHO) global status report on the public health response to dementia estimated that the global cost of dementia in 2019 amounted to 1.3 trillion US dollars [4], a number expected to increase to about 2.8 trillion in 2030. Of these, 213.2 billion US dollars (16.2 %) can be attributed to direct medical costs (such as hospital care, medicines, diagnostic tests and clinic visits), while 448,7 (34.2 %) arise from services outside the medical care system, i.e., the direct *social* costs (such as community-based services and long-term institutional care). These numbers show challenging times ahead for any healthcare system, and there is an urgent need to plan care infrastructure accordingly, optimising existing caregiving structures while maintaining high-quality care.

The WHO global status report also shows that informal caregivers of PLWD by far incur the largest cost of dementia, constituting almost half of the total costs at the global scale at 651.4 billion US dollars [4]. Although informal care costs are more difficult to measure (and are usually estimated on the basis of the time required by informal caregivers such as family to provide care and assistance to their loved one with dementia [4]), WHO estimated that informal carers spent over 89 billion hours providing care and support, meaning approximately five hours per day per PLWD [4]. With the ageing population and predicted rise in the proportion of PLWD, this figure increases to about 133 billion hours, or eight hours per day providing care for a person with dementia [4]. The growing awareness of the importance of informal caregivers to the sustainability of community care has resulted in increased attention to the needs of these carers across several European countries [8]. Nevertheless, services for carers have been criticised for being irregular, ad hoc and reactive [8]. Clearly, efforts are needed to optimise home-based caregiving as well, ensuring that PLWD can live well at home for as long as possible before transitioning to institutional care. This need is based on more than just economic considerations; the concept of ageing-in-place reflects the preferences of most older adults, who generally wish to live in their own homes as long as possible [9-11]. This is also true for PLWD [12-14], who can express their needs and preferences consistently, even in advanced stages of dementia [15-18]. However, ageing-in-place requires educated informal caregivers, or professional support at home [19].

In the efforts of promoting ageing-in-place, it is important to note that the quality of the caregiver-care recipient relationship in a dementia context is recognised as an important predictor of institutionalisation of PLWD, where findings indicate that a good relationship in the caregiving dyad decreases the risk of nursing home placement or institutionalisation [20-22]. Caregiving dyads can be defined as "A caregiving relationship consisting of a caregiver and a care recipient" [23], where for the purpose of this thesis, PLWD are encompassed in the term 'care recipient' while the term 'caregiver' can include either a professional caregiver or an informal caregiver. Caring for a person diagnosed with dementia requires more than financial and time-related resources of the caregiver. It also requires physical, emotional and social resources [24-27]. Better care provision can be achieved through the maintenance of the mental and physical health of caregivers of PLWD while deterioration of relationships and accumulation of interpersonal burdens have been found to lead to emotional exhaustion [27]. However, empirical evidence has demonstrated that taking on a role as a caregiver of PLWD can also have positive benefits, including a sense of personal accomplishment and gratification, feelings of mutuality and a sense of personal growth and life purpose [28]. One crucial source of such positive aspects of caregiving is the participation in social activities [29-31] by finding a balance between capabilities and limitations imposed by the disease [31-33].

Given the already existing shortage of skilled workers faced by many healthcare systems with the growing demand for long-term care (LTC) along with the ageing population [34], technological solutions are increasingly being sought as strategies to optimise existing caregiving structures [34-37]. Research activities on technological solutions in nursing and caregiving are flourishing, driven forward by the expectation that these might help people in need of care to improve their health and quality of life (QoL), while also supporting caregivers by simplifying caregiving routines or assisting in direct care [34, 38]. Examples include information flow systems (e.g., electronic health/medical records) [39, 40], remote care technologies (e.g., telemedicine/telehealth) [41-43] and monitoring systems (e.g., sensors) [44, 45]. Alongside technological developments to optimise institutional caregiving, major technological strides have also been made in community caregiving. Here, technology has been identified as one tool in dementia caregiving to improve independent living, supporting the QoL for both the care recipient and the informal caregiver, while promoting the safety and autonomy of PLWD [35, 46]. Examples include smart home solutions [47-49], GPS monitoring [50-52] and telemedicine [53-55]. Furthermore, technology may offer new ways of reducing caregiver burden through information provision and social contact [56].

In the efforts of supporting caregivers of PLWD, the role of technology in promoting social participation is receiving increasing focus in research and clinical practice [30, 50, 57, 58], where we have witnessed technical innovations such as social robots [59-61], technology-based reminiscence [62, 63] and even virtual reality technology for PLWD [64, 65]. Despite the increasing attention on social participation for PLWD using technology, there is still a gap in the knowledge of how technology-supported social participation in dementia caregiving dyads may support relationship sustenance and QoL for both dyad members. This thesis will address this gap by complementing and extending the literature by investigating how dementia caregiving relationships may be upheld by utilising technological innovations for social participation and thus contribute to the accumulation of evidence across study designs, settings and populations.

1.2. Cumulative Dissertation Outline

This dissertation describes the research context of the four individual studies conducted. This introductory **Chapter One** is followed by literature-based theoretical and empirical positioning of the present state of the art of the topic in **Chapter Two**. The second chapter describes the theoretical foundations of social health, relationship-centred care approaches and enrichment processes in caregiving before introducing the role of technology in promoting quality of life and well-being for people living with dementia and their caregivers. **Chapter Three** presents the overarching research question of this thesis as well as the objectives of the individual articles encompassed in this dissertation. **Chapter Four** outlines the methodological approach of the individual studies, followed by a brief description of the findings in **Chapter Five. Chapter Six** discusses the thesis scope and key findings as well as the thesis strengths and limitations. Implications for practice, research and policy are summarised in **Chapter Seven,** which also formulates final conclusions and future outlook.

1.3. List of First-Authorship publications comprised in this Dissertation

Against the background outlined above, this cumulative dissertation examines the possibilities and limitations of technology-driven solutions supporting dyadic relationships when one dyad member has dementia. This thesis is based on a scoping review, a systematic literature review, and empirical studies using primary and secondary research data.
This cumulative dissertation is composed of five individual papers (publications as first author). All papers have been published in peer-reviewed, international journals.

Paper I.

The first article in this dissertation is a systematic literature review.

Citation: Hoel, V., Feunou, C.M. and Wolf-Ostermann, K. *Technology-driven solutions to prompt conversation, aid communication and support interaction for people with dementia and their caregivers: a systematic literature review.* BMC Geriatrics, 2021. **21**(1): p. 157.

Author contribution:

The review was conceived and planned by VH in conjunction with CM and KWO. An initial literature search strategy was developed and conducted by VH based on identified key papers. The search strategy was updated and revised in collaboration CM. VH and CM thereafter conducted the search and screened the literature for eligibility independently. Discrepancies between VH and CM were discussed until consensus was achieved, and there was no need for a third-party decision on conflicts. VH conducted the data extraction, interpreted the literature and wrote the first draft of the manuscript. CM and KWO critically reviewed the drafts and the final manuscript. VH led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript, which was advised and supported by KWO.

Paper II.

The second article is a cross-sectional study including data collected in a national online survey of German nursing homes.

Citation: Hoel, V., Seibert, K., Domhoff, D., Preuß, B., Heinze, F., Rothgang, H., Wolf-Ostermann, K. *Social Health among German Nursing Home Residents with Dementia during the COVID-19 Pandemic, and the Role of Technology to Promote Social Participation.* International Journal of Environmental Research and Public Health, 2022. **19**(4): p. 1956.

Author contribution:

The study was conceived and planned by VH in conjunction with KS, DD and KWO. The online questionnaire was developed and designed by KS and DD, which was reviewed and approved by all authors. VH independently analysed the collected data relevant to address the research questions, which was reviewed and guided by KWO. VH developed the graphics and wrote the first draft of the manuscript, which was critically reviewed by KW, DD, BP, FH, HR and KWO. VH led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript, which was advised and supported by all co-authors.

Paper III.

The third article in this dissertation is a pilot case study, reporting on preliminary findings from the feasibility study encompassed in ***Paper IV.***

Citation: Hoel, V., K. Wolf-Ostermann, and E.A. Ambugo, *Social Isolation and the Use of Technology in Caregiving Dyads Living With Dementia During COVID-19 Restrictions.* Frontiers in Public Health, 2022. **10**.

Author contribution:

Throughout the research, VH delegated tasks and organized the work of the research assistant who participated in the research, and trained him regarding communicating with people living with dementia. The work of the research assistant included reaching out to identified collaboration partners, interviewing participants, transcribing and translating the semi-structured interviews. The data protection concept and ethics application were developed and drafted by VH, supported by KWO. VH also identified collaboration partners to support participant recruitment, wrote the participant information sheets, selected the outcome measurement tools, designed the interview guides and administered the data collection tools. VH and EAA independently coded the interview transcripts and discussed the identified themes until consensus was achieved. VH wrote the first draft of the manuscript, which was critically reviewed by EAA and KWO until all authors agreed on the final version. VH led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript, which was advised and supported by EAA and KWO.

Paper IV.

The fourth article in this dissertation is a mixed-methods feasibility trial, reporting on the usability and impacts of I-CARE on community-dwelling dementia caregiving dyads.

Citation: Hoel, V., Ambugo, E.A. and Wolf-Ostermann, K. *Sustaining Our Relationship: Dyadic Interactions Supported by Technology for People with Dementia and Their Informal Caregivers.* International Journal of Environmental Research and Public Health, 2022. **19**(17): p. 10956.

Author contribution:

Throughout the research, VH delegated tasks and organized the work of the research assistant who participated in the research, and trained him regarding communicating with people living with dementia. The work of the research assistant included reaching out to identified collaboration partners, interviewing participants, transcribing and translating the semi-structured interviews. The data protection concept and ethics application were developed and drafted by VH, supported by KWO. VH also identified collaboration partners to support participant recruitment, wrote the participant information sheets, selected the outcome measurement tools, designed the interview guides and administered the data collection tools. VH independently analysed the quantitative data, which was critically reviewed and supported by KWO. In the qualitative component, VH and EAA independently coded the interview transcripts and discussed the identified themes until consensus was achieved. VH wrote the first draft of the manuscript, which was critically reviewed by EAA and KWO until all authors agreed on the final version. VH led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript, which was advised and supported by EAA and KWO.

Paper V.
The fifth and final article in this dissertation is a scoping review.

Citation: Hoel V., Koh, W.Q. and Sezgin, D. *Enrichment of dementia caregiving relationships through psychosocial interventions: A scoping review*. Frontiers in Medicine, 2023. **9**:1069846.

Author contribution:
The review was conceived and planned by VH in conjunction with WQK and DS. An initial literature search strategy was developed and conducted by VH based on theoretical and empirical literature, which was thereafter revised and refined in collaboration with an expert research librarian. VH and WQK thereafter screened titles/abstracts and full-text articles for eligibility independently. Discrepancies between VH and WQK were discussed until consensus was achieved, and any discrepancies in the full-text screening phase were resolved by DS. VH and WQK independently piloted 20 % of the data extraction before VH completed the remaining 80 %, verified by WQK. The charting and analysis of extracted data was conducted by VH, again verified by WQK and discussed with DS. VH wrote the first draft of the manuscript, which was critically reviewed by WQK and DS before VH and WQK revised the drafts and wrote the final version submitted for publication. VH led the authors' responses to the reviewers' feedback, collated the response and redrafted the final manuscript, which was advised and supported by WQK and DS.

1.4. Publications and Research Outputs related to the work of this Thesis

Oral Presentations:

- **Hoel, V**., Seibert, K., Domhoff, D., Preuß, B., Heinze, F., Rothgang, H., Wolf-Ostermann, K. (June 2022) Social health in nursing home residents with dementia during COVID-19, and the role of technology to promote social participation. Part of the symposium "Lessons learned from the COVID-19 Pandemic in Long-Term Care – An International Perspective. 26th Nordic Congress of Gerontology. Odense, Denmark."
- **Hoel, V.**, Steinert, L., Wolf-Ostermann, K., Schultz, T., Ambugo, EA. (December 2021). "Dyadic coping through COVID-19 with and without social technology: Experiences from community-dwelling people with dementia and their spouse." 31st Alzheimer Europe Conference. Virtual, Utrecht, The Netherlands.
- **Hoel, V.**, Seibert, K., Domhoff, D., Preuß, B., Heinze, F., Rothgang, H., Wolf-Ostermann, K. (December 2021). "Social health among German care recipients with dementia during COVID-19, and the role of technology to promote social participation." 31st Alzheimer Europe Conference. Virtual, Utrecht, The Netherlands

- **Hoel, V.**, Steinert, L., Wolf-Ostermann, K., Schultz, T. (November 2021). "Technology-Driven Dyadic Interaction Support for Community-Dwelling People with Dementia and Family Caregivers." Part of the symposium "Strategies to Design Technology Promoting Social Participation of People with Dementia and Their Caregivers." The Gerontological Society of America's Annual Scientific Meeting. Virtual and Phoenix, Arizona, USA
- **Hoel, V.**, Steinert, L., Wolf-Ostermann, K., Schultz, T., Ambugo, EA. (September 2021). "Social isolation and the use of technology in caregiving dyads living with dementia during COVID-19 restrictions." Part of the symposia "Häusliche Pflege und Versorgung während einer Pandemie – Ergebnisse quantitativer und qualitativer Forschung." Gemeinsame Fachtagung der der Deutschen Gesellschaft für Gerontologie und Geriatrie (DGGG). Virtual and Berlin, Germany

Poster Presentations:

- **Hoel, V.**, Steinert, L., Wolf-Ostermann, K., Schultz, T., Ambugo, EA. (July 2021). "Technology-driven dyadic interaction in caregiving." Alzheimer's Association International Conference 2021. Virtual and Denver, USA
- **Hoel, V.**, Steinert, L., Wolf-Ostermann, K., Schultz, T. (December 2020). "Technology-driven dyadic interaction enhancement for community-dwelling people with dementia and their family members." MindTech2020: Digital Mental Health in the Age of COVID-19. Virtual, United Kingdom

Publications and Research Outputs related to the Dissertation:

- Koh, W.Q., Casey, D., **Hoel, V.**, Toomey, E. *Strategies to Implement Pet Robots in Long-Term Care Facilities for Dementia Care: A Modified Delphi Study.* Journal of the American Medical Directors Association, 2022.
- Koh, WQ., Casey, D., **Hoel.**, **V**., and Toomey, E. *Strategies for implementing pet robots in care homes and nursing homes for residents with dementia: protocol for a modified Delphi study.* Implement Sci Commun, 2022. **3**(1): p. 58.
- Budak, KB., Atefi, G., **Hoel, V.**, Laporte Uribe, F., Meiland, Teupen, S., Felding, SA., and Roes, M. *Can technology impact loneliness in dementia? A scoping review on the role of assistive technologies in delivering psychosocial interventions in long-term care.* Disability and Rehabilitation: Assistive Technology, 2021: p. 1-13.
- **Hoel, V**., von Zweck, C., and Ledgerd, R. *Was a global pandemic needed to adopt the use of telehealth in occupational therapy?* Work, 2020
- **Hoel, V**., von Zweck, C., and Ledgerd, R. *The impact of Covid-19 for occupational therapy: Findings and recommendations of a global survey.* World Federation of Occupational Therapists Bulletin, 2021: p. 1-8.

Chapter Two. Theoretical and empirical positioning

2.1. Chapter introduction

This literature-based chapter positions the subject of this cumulative dissertation theoretically and empirically. The literature included in this chapter is based on that used for the published papers comprising this thesis but also includes sources identified in additional research for the preparation of this dissertation. In this chapter, our understanding of social health in a dementia caregiving context will be presented, following the operationalised definition posed by the INTERDEM Social Health Taskforce (Section 2.2). The relationship between social health and relationship-centred care approaches is outlined (Section 2.3), with Section 2.4 advocating the need for a conceptualisation of positive experiences in caregiving. An operationalised, contextualised model of enrichment processes in dementia caregiving relationships is outlined as a potential theoretical framework (Section 2.5). Thereafter, a rationale is provided as to why the theoretical framework of enrichment processes in caregiving may be helpful in guiding research on technology-supported interventions aiming to support dyadic relationships in dementia caregiving (Section 2.6). Existing gaps in current knowledge concerning the potential of technology to facilitate social health and relationship sustenance in dementia caregiving dyads are identified before the chapter concludes with the summarised scientific knowledge contribution of this cumulative dissertation (Section 2.7).

2.2. Social health and person-centred care in dementia

In 2013, the inter-governmental political forum G7 (then the G8) set an ambitious goal committing to identify a cure or disease-modifying therapy for dementia by 2025 [66, 67]. With the current state of scientific knowledge, there is no guarantee that such a remedy will be found within the next few years. With no cure in sight, more focus has been directed on how to live as well as possible with dementia [31, 32, 68]. Historically, dementia research and practice have been dominated by biomedical models focusing on symptoms and disability and a negative discourse influencing public perception of the disease [69]. This reductionistic understanding of dementia has also influenced research on caregivers, where stress and burden perspectives [70-72] or stress-coping models have provided the dominant theoretical frameworks [73-78] (elaborated below in Section 2.4). Although it is essential to understand the pathology and negative consequences of dementia, this reductionistic understanding of the disease has been criticised for neglecting the remaining capabilities of people living with dementia (PLWD) and the possibilities to compensate for the deficits [33]. More focus has since been directed at how people can adapt cognitively, emotionally and socially to the changes that dementia entails [31] and how PLWD and their caregivers can be supported in maintaining well-being [79-82]. A pillar in this shift in focus is the concept of social health [31-33, 83]. This concept emerged in the context of a critique and debate on the World Health Organization's (WHO) definition of health as "a state of complete physical, mental and social well-being" [84]. The main criticism of WHO's definition concerned the absoluteness of the word "complete" concerning well-being and was re-conceptualised by

Huber and colleagues in 2011 as "the ability to adapt and self-manage [83]. The idea behind the reconceptualised concept was to provide a more holistic and dynamic understanding of health. Hence, social health was conceptualised as the influence of social and environmental resources in finding a balance between capacities and limitations, which relates to an individual's abilities to adapt to different social situations and act appropriately in various settings [31, 68, 83].

In order to create a more balanced view of dementia and a more dementia-friendly society, the concept of social health has been adopted as an alternative frame to the one-sided focus on symptoms and disability towards the capacity and potential of PLWD [32]. The concept of social health was operationalised and contextualised to dementia in 2016 by the INTERDEM Social Health Taskforce [31, 32] to contain three social health dimensions: i) capacity to fulfil potential and obligations; ii) ability to manage life with some degree of independence; and iii) participation in social activities. The first dimension relates to the abilities of PLWD to function in society according to their competencies and talents (i.e., 'potentials') in the best possible way to meet social demands (i.e., 'obligations') on all societal levels. This dimension encompasses a shift in focus from diminishing capabilities to focusing on remaining capacities and strengths; relating to normalcy rather than a reductionist view of dementia. The second dimension encompasses one's ability to preserve autonomy, solve daily life problems, and adapt and cope with the practical and emotional consequences of dementia. Remaining autonomous and able to adapt and cope with daily difficulties by employing compensation strategies, problem-solving and adapting the environment are central aspects of effective life management within the context of dementia. The third and final dimension involves being occupied or engaged in meaningful activities and social interactions, having social ties and relationships that are meaningful to PLWD. The emotional aspect in the operationalisation of social participation is considered an essential building block of social health [31, 32] and stands as the central pillar of this doctoral dissertation.

In addition to the core elements of each social health dimension, *influencing factors* and *interventions* of each dimension were inventoried by the INTERDEM Social Health Taskforce [31]. The identified factors influencing each dimension were categorised according to four categories, including personal factors (e.g., sense of coherence, life history or (pre-morbid) personality), disease-related factors (e.g., the severity of cognitive disabilities or comorbidities), social factors (e.g., social support, caregiving relationships or reciprocity in relationships) and environmental factors (e.g., living arrangement and availability and accessibility of assistive technology). Finally, the Social Health Taskforce identified focus areas of interventions that intend to optimise, promote or support each operationalised social health dimension for PLWD and their caregiver(s).

Some intervention focus areas identified aimed at the social health dimension itself, others at facilitating factors [31]. Identified focus areas of interventions within the dimension of 'capacity to fulfil potential and obligations' included interventions that potentially build capacities and/or enhance resilience. Examples included advanced care planning, assistive technologies to compensate for functional disabilities, and dementia-friendly communities. Interventions aimed at supporting PLWD's 'ability to manage life with some degree of independence' were divided into those intended for the care recipient, the caregiver, or both. These included cognitive rehabilitation therapies, exercise and psychomotor therapy, staff awareness training and support groups [31]. A key element of interventions within the third dimension ('participation in social activities') was identified by INTERDEM as serving as a communication channel for PLWD to engage, interact and talk with others – referred to as collective engagement. Contrary to problem-oriented interventions, the focus here lies on the individual and interventions are generally aimed at positive experiences and occupation in meaningful activities [31]. The published works comprising this dissertation fall within this inventoried category of social health.

All three dimensions encompassed by social health are closely related to the concept of person-centred care, which includes the recognition that the personality of the person with dementia is increasingly concealed rather than lost; personalisation of the individual's care and environment, and prioritising the relationship as much as care tasks [85]. Developments in dementia care and research have been substantially influential in developing models of person-centred practice [86]. Most notable of these is the work of Tom Kitwood, a leading contributor to the development of the person-centred care model in dementia. A central theme in his work is the notion of safeguarding the 'personhood' of PLWD, defined as 'a standing or status bestowed upon human beings by others in the context of relationship and social being' [87] (p. 8). Through this definition, Kitwood recognises and emphasises relational capacity and interdependence as fundamental aspects of personhood [88], which closely aligns with the INTERDEM Social Health Taskforce's operationalisation of social health in dementia.

2.3. Relationship-centred care and positive perspectives on caregiving

Concurrently, person-centred care and personhood became highly influential in research, policy, and practice, not only within dementia but in various caregiving settings [70]. However, along with the increasing advocacy of person-centred care during the last two decades [85, 86], the caregiving philosophy has also been subjected to criticism; current person-centred interventions in dementia have been criticised for being implicitly individualistic [78, 89] and insufficiently include the caregivers [78, 88, 90, 91]. Although the relationship between PLWD and caregivers is now seen as instrumental to the personhood of PLWD [70, 92, 93], relationships in dementia caregiving remained the overlooked variable in many studies [92, 94, 95]. Since then, relationship-centred care has gained increasing recognition as a complementary model to person-centred approaches by adequately including the relationship dynamic between the care recipient and their formal or informal caregiver [96, 97].

Despite the shift in focus toward remaining capabilities encompassed within social health, the common symptoms and dementia trajectory might change the conventional relationship of the caregiving dyad [98]. The relational dynamic between PLWD and their caregivers can be influenced by progressive memory loss, a decline in cognitive functioning and personality changes [98]. This could leave informal caregivers (e.g., family members) feeling they are caring for someone other than the person they once knew [98]. The common symptoms and dementia trajectory influence the conventional relationship of the caregiving dyad in formal relationships as well (e.g., between PLWD and nursing home staff). Long-term care (LTC) facility settings constitute a unique healthcare environment in terms of residents' length of stay and the subsequent relationships built between caregivers and care recipients. This, in turn, directly impacts the experience of both members of the caregiving dyad [99], with research showing an association between meaningful nurse-resident relationships and staff retention. Killick and Allan raised the same argument in their book *Communication and the care of people with dementia*, stating that formal caregivers mostly deeply value relationships and connections formed with their patients [100]. Whether one emphasises the person-centred or the relationship-centred approach to caregiving, personhood has been found to be sustained in relationships where both caregiver and care recipient experience a close emotional bond [101-103]. Returning to the concept of social health, one can argue that opportunities for PLWD to connect with caregivers constitute a key part of the third social health dimension.

Opportunities to socially connect are also considered an imperative goal for psychosocial interventions [75, 104, 105], defined as "interpersonal interventions concerned with the provision of information, education, or emotional support together with individual psychological interventions addressing a specific health and social care outcome" [106] (p. 108). Shared activities meaningful to both dyad members and caregiving focusing on the interactive capabilities of PLWD provide important ways to enhance social connections [70, 107, 108]. Examples include music therapy [109], individualised reminiscence therapy [110], and staff education programs [111]. Research shows that psychosocial interventions providing positive social interactions for PLWD and their informal caregivers may support caregiving dyads adapting and living well with dementia [107, 108]. These opportunities for positive experiences in caregiving are also highly relevant in formal contexts; psychosocial interventions that support social interactions between PLWD and formal caregivers appear to have positive relational impacts, as they can support the development of connection and reciprocity [112-114]. Moreover, engagement in social activities perceived as meaningful can increase staff satisfaction, which again can feed back into the relationship with PLWD [114-116].

2.4. Conceptualising a positive discourse of caregiving

Interventions focusing on positive aspects of caregiving are receiving increasing attention [75, 88]; however, there is a need to conceptualise this focus [75, 117]. Applying theoretical frameworks appropriate for dyadic processes, in general, has been pointed out as essential in expanding our understanding of the diverse results in dementia research [73], as they might lead to innovative approaches to working with caregiving dyads [117]. Nevertheless, theory-based research on dementia caregiving dyads is sparse [73], with influential theories traditionally leaning towards stress-coping models [73-78] focusing on burden and strain [70-72] rather than taking on a positive discourse. Examples include studies based on variations of the transactional stress and coping theory developed by Lazarus and Folkman [76, 77, 118, 119]. This theory postulates that adaptation to stress is mediated by two variables – appraisal of the stress in question and the coping strategies of the individual [73, 118]. However, a limited body of literature supports this theory in dementia research [73, 77], which limits the predictive usefulness in dementia caregiving. In addition to the emphasis on coping with negative caregiving aspects, this theory is directed only at the caregiver, not the afflicted dyad as a unit. Focusing merely on individual-level coping fails to consider the relationship between the caregiver and care recipient, which profoundly impacts caregivers' adjustment [120].

This issue is addressed in the theoretical construct of family adaptation [121], which includes dyadic variables to comprehend the relationship between caregivers and care recipients [120]. Family adaptation is one of three dimensions encompassed in the Circumplex Model, describing differences between functional (and less functional) relationships, where family adaptability is described as the ability of family systems to change the power structure, relationship roles and rules in response to situational and developmental needs [120, 121]. The relevance of family adaptation in spousal dementia caregiving relationships has been demonstrated by Majerovitz and colleagues, who found that less adaptable caregivers showed a correlation between illness-related stress and depression while more adaptable caregivers had no such associations [120]. They hypothesised that less adaptable caregivers might have greater difficulties adjusting their daily routines in response to the changing demands of caring for someone with dementia. The concept of family adaptation seems to be a useful model concerning caregiver stress while sufficiently including dyadic variables; however, the focus lies predominantly on negative aspects while ignoring positive implications and gains from caregiving. Several examples in the body of research literature attempt to integrate positive aspects of caregiving into the same stress-coping models used to understand *negative* caregiving aspects [122-124]. However, negative and positive aspects of caregiving have been found not to be polar opposites on the same continuum, but rather appear to be separate dimensions of the caregiving experience [122]. Criticism points out the difficulties of conceptualising positive perspectives on caregiving within theoretical frameworks focusing on coping with stress [75, 125], making them incongruous with interventions and dementia research focusing on social health.

One alternative approach taking on a positive perspective of caregiving as well as sufficiently including both dyad members is the theory of 'couplehood' [70], developed by Hellström and colleagues in their work to explore strategies that spouses use to live positively when one partner has dementia. Here, the dyadic caregiving experience could be improved through enhanced strategies for sustaining couplehood and maintaining involvement by focusing on the strengths of the PLWD [70, 117]. This is closely related to the first dimension of social health, making the couplehood approach highly relevant in dementia research and clinical care, focusing on the positive sides of caregiving. By combining relationship-centred approaches with the concept of social health focusing on remaining capacities and strengths, interventions with a positive discourse on caregiving may lead to relationship gains [105, 122]. However, the couplehood approach has certain limitations as to the applicability in positive aspects of dyadic caregiving relationships. The model is developed for spousal relationships in dementia and does not include other family caregivers. Variations in dyadic structures can cause significant differences in clinical outcomes for both dyad members [82, 126, 127], necessitating broadening the concept.

2.5. Enrichment in dyadic relationships

The theoretical concept of 'enrichment' offers a broader inclusion of different typologies of dyadic relationships while maintaining a positive discourse on caregiving. The model of enrichment processes in family caregiving was developed by Cartwright et al. back in 1994 [105], who criticised the traditional negatively oriented caregiving theories. They argued that directing supportive efforts only towards the reduction of burden and strain could lead caregiving relationships to become more problematic while ignoring opportunities to enhance the satisfaction gained from the relationship. Enrichment, on the other hand, defined as "the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient" [105] (p. 32), builds on positive characteristics and capacities of individuals, closely related to the vision of social health.

In Cartwright and colleagues' model, enrichment includes two main categories. The first refers to 'customary routines', which are patterned and predictable parts of everyday life activities. These activities include rituals well-known to the dyad members, breeding a sense of comfort, such as bedtime or dining rituals. The second enrichment category includes 'innovative routine breakers', referring to activities outside the ordinary routine that provide additional stimulation to the day. The interventions reported in the body of work included in this dissertation can be considered as such, as they evolve around tools outside routine care to promote social stimulation and engagement in shared activities outside routine care. Within both 'customary routines' and 'innovative routine breakers', enrichment processes in caregiving encompass three core elements: i) *acquiring symbolic meaning*; ii) *performing activity*; and iii) *fine tuning*. The first core element, *acquiring symbolic meaning*, refers to the significance, value or intent of an activity or an object, with the symbolic property reflecting meaning that transcends the utility of the given object or activity [105]. The second core element of the enrichment model, *performing activity*, was described by Cartwright and colleagues as the observable behaviours in the caregiving situation. The final core element involves efforts to accommodate the dementia trajectory and personal histories in creating enrichment and is referred to as *fine tuning* in the enrichment model.

The three enrichment core elements were operationalised and contextualised to a dementia caregiving context in *Paper V* as a part of a scoping review charting the evidence of what constitutes enrichment in dementia caregiving. By identifying intervention components falling under the three operationalised enrichment core elements, psychosocial interventions were found to contribute to enrichment in a multitude of ways. The scoping review also found that the nature of the caregiving relationship (i.e., whether it is formal or informal) influences the ways in which enrichment can be generated, but these factors were outside the scope of *Paper V*. However, the enrichment model also includes antecedent factors, which revolve around the individual characteristics of the dyad members (i.e., personal history and frailty trajectory) and their relationship (i.e., the quality of their caregiving relationship and the caregiving situation). The nature of the caregiving relationships (e.g., being formal or informal, or the relationship quality) constitutes a major contextual factor influencing the core enrichment elements for both dyad members.

Research suggests that the relational nature influences the relationship quality and the experiences of both dyad members living with dementia [128]. These aspects can be regarded as outcomes of enrichment impacting the individual dyad members and their shared relationship. Thus, Cartwright et al. included consequences of enrichment in their model for the caregiver (i.e., rewards and identity sustenance), care recipient (i.e., comfort and identity sustenance) and the dyad as an entity (i.e., relationship sustenance). The core elements of enrichment, taken together with the antecedent and consequential factors, are all dependent on the meaning ascribed to care [129]. Cartwright and colleagues hence argue that enrichment should constitute a major therapeutic intervention whereby caregiving dyads are encouraged and assisted in maintaining customary or pleasurable routines and developing new ways in which everyday life activities can attain new symbolic meaning [105, 129].

Cartwright and colleagues' linking of meaning and pleasure with a satisfying relationship for both dyad members in both ordinary and extraordinary activities highlights the integral nature of these concepts [129], firmly placing enrichment in caregiving as a linchpin in the relationship-centred care approach. Like other relationship-centred approaches, the concept of enrichment is attractive because it may provide caregivers and care recipients with opportunities to experience the positive meaning of caregiving while potentially enhancing the well-being of both dyad members [117]. Utilizing the enrichment model is also an opportunity to reframe the negative societal discourse on dementia and ageing [32] and sufficiently focus on both dyad members and the relationship dynamics.
Nevertheless, although the enrichment model includes more dyadic typologies than the couplehood approach, one important dyad type is not included in the model – the formal (i.e., paid) caregiving relationship. As mentioned in the introductory chapter, 34.2 % of the global cost of dementia is predicted to incur in community-based services and long-term institutional care in 2030 [4]. Long-term relationships between caregivers and care recipients are being built in these healthcare environments, which in turn directly impacts the experience of both members of the caregiving dyad [99]. The relevance of conceptualising positive perspectives on caregiving does not decrease in formal caregiving relationships; care recipients need support to maintain quality of life (as the need for support might be even more prominent in formal caregiving settings where care recipients often are frailer

compared to community-dwelling PLWD). Reciprocal and positive caring relationships have the potential to make a difference in the life they experience [90].

Therefore, the enrichment model was broadened to include formal and informal relationships to make it applicable across caregiving settings. This process is elaborated accordingly in Chapter Four (Methodology) and *Paper V*. A broader conceptualisation of enrichment to include formal and informal caregiving relationships may help guide the development of interventions seeking to facilitate shared and personal gains in caregiving relationships. Although the model of enrichment is not extensively utilised in dementia caregiving research, using this broader conceptualisation when planning and evaluating psychosocial interventions in dementia might lead to innovative approaches when working towards enhancing the social health and well-being of the dyad as a unit of attention.

2.6. Social technology's potential to enrich caregiving relationships

In the sphere where the concept of social health and dementia caregiving meet, there has been an immense growth in research revolving around technology [130], as the potential of technologies to support PLWD and their caregivers across caregiving settings has gained the attention of policymakers and governments [130, 131]. The usage of digital technologies to facilitate the achievement within one or several of the operationalised dimensions of social health has been gaining increasing attention [2, 15, 30, 57, 131-137]. Technology contributing to these dimensions of social health can therefore be referred to as social technology by facilitating contact between people. In the body of work in this thesis, social technology is defined as "any technology that facilitates social interactions and influences social processes between people." [138] (p. 2). Despite this, the technological progress within the third dimension, especially in supporting social interaction and communication for this patient group, is still in its infancy [35]. Moreover, to the best of my knowledge, no technological solutions have been explicitly utilised to facilitate *enrichment* in dementia caregiving dyads. A possible explanation is that most technological solutions to cognitive problems associated with dementia have mainly focused on assistive technology, cognitive rehabilitation and physical training [112]. These technologies are undoubtedly crucial in promoting the first two operationalised dimensions of social health (i.e., 'capacity to fulfil potential and obligations' and 'ability to manage life with some degree of independence'), but less focus has been given to the third dimension ('participation in social activities'). Interventions may be well-supported by utilising social technology as a means to an end to help maintain social relationships and generate enriching experiences in caregiving.

Although there is a vast body of research literature on technological solutions for communication support in dementia, these solutions often tend to focus on conversational performance, such as targeted words and content relevance, rather than positive experiences generated from these conversations [139-143]. Augmentative and Alternative Communication (AAC), an integral part of medical speech-language pathology practice [139], stands as a typical example of such support. Considering that communication is a collaborative process [107], it is expected that interventions like AAC mutually influence both dyad members engaged in the conversation. Therefore, if we are to keep in line with relationship-centred approaches, interventions using AAC technologies also need to account for potential outcomes on the conversation partner of PLWD when using communication aids. Here, the enrichment model may guide the development and implementation of psychosocial intervention in dementia using technology to promote caregiving relationships. Promising results are already emerging around technologies aiming to facilitate social interaction and support dyadic communication in the context of dementia. Several studies indicate that by utilising technological devices to aid conversations, caregivers of PLWD experience a lowered burden in initiating and maintaining conversations [116, 144, 145]. Communication and social interaction are not only the pillars of the third operationalised dimension of social health but also permeate the whole concept. By including social technology as a third party in social interactions, digital devices have the potential to turn the conversation into an enriching interactive experience without demanding any special education or skillset of the participants.

The COVID-19 pandemic has undoubtedly been a major driving factor in the increased interest in technological solutions in neurological disease management and dementia caregiving [57, 146-149]. This includes assistive technologies supporting independent living at home and telehealth technologies facilitating remote consultations, interventions and monitoring [42, 146, 148]. Community-dwelling caregiving dyads have experienced the breakdown of supportive systems and respite services such as Day Care Centres (DCCs) [150-152], while nursing home residents with dementia and their family members faced restricted visitation access and the discontinuation of social activities [153-155]. Consequently, severe social isolation was observed in both formal and informal caregiving settings. The aftermath of the COVID-19 pandemic has exposed an urgent need for effective technological solutions to safeguard the social health of PLWD and those who care for them in times of crisis. Not merely technology that connects PLWD and their loved ones remotely (when in-person contact is impossible), but also technology that can facilitate an *interpersonal* connection between PLWD and those in their immediate surroundings by facilitating enriching social interactions and providing a joint platform to connect.

From the perspective of enrichment processes in caregiving, one can argue that the global pandemic is an unprecedented influencing (antecedent) factor regarding how enrichment may be generated in dyadic relationships and the outcomes (consequences) of these processes. COVID-19 will likely influence dementia caregiving dyads for the foreseeable future. Technological solutions may provide innovative ways to support social participation and relationship sustenance for caregiving dyads by supporting enrichment in 'customary routines' (e.g., assistive technologies) or offering 'innovative routine breakers' through technologies such as those included in the body of work in this dissertation.

2.7. Knowledge gaps and scientific contribution of this Thesis

This literature-based theoretical and empirical chapter reveals the following knowledge gaps in the body of existing literature:

- Dementia caregiving dyads encompass a care recipient and caregiver; relationship-centred care models have emerged in response to criticism against the person-centred approach for not adequately including the caregiver. The quality of the caregiving relationship influences both dyad members regardless of the nature of the relationship, calling for increased focus on activities providing positive experiences. Nevertheless, strategies are lacking to maintain or improve the quality of caregiving relationships through enriching experiences.
- The concept of enrichment in caregiving was first proposed by Cartwright and colleagues in 1994 but has not been utilised in dementia research. By operationalising and contextualising the concept of enrichment in dementia caregiving, relationship sustenance can be supported by psychosocial interventions aiming to enhance positive experiences in the caregiving relationship and thereby support the maintenance of good-quality relationships.
- In the context of social health, enrichment, and relationship-centred care approaches in dementia, there is an unexploited potential in technology to facilitate social participation for both PLWD and their caregivers. Despite immense technological strides in communication support for cognitive impairments, there is a gap in the knowledge of how technology might support relationship sustenance and positive experiences in caregiving through facilitated communication and social interaction.
- In light of the global COVID-19 pandemic, the need for effective technological solutions to safeguard the social health of PLWD and their caregivers has been exposed. The extreme social isolation in the community and institutional care settings following the preventive measures against SARS-CoV-2 has shed light on the knowledge gap on safeguarding social health without compromising the physical health of society's vulnerable. Technology might be the solution to ensure the achievement of both physical and social health in times of crisis.

This cumulative dissertation contributes to knowledge through the identification of contextual factors impacting the uptake and effects of technological solutions to support communication and facilitate social interaction and by illustrating how different methodological approaches can be utilised to investigate technology supporting social participation and dyadic relationships. By building upon and extending an existing theoretical model using empirical research and the spearheaded work of the INTERDEM Social Health Taskforce to operationalise the concept of enrichment in dementia caregiving, future dementia research can utilise the extended model when developing and implementing psychosocial interventions aiming to improve or sustain caregiving relationships. By focusing on enrichment in caregiving relationships, this oeuvre contributes to scientific knowledge by identifying how technological solutions may be utilised to support social interaction and communication, thereby facilitating social participation and relationship sustenance in dementia caregiving dyads. This cumulative dissertation addresses a literature gap by focusing on how social technological may influence the relational dynamic between the care recipient with dementia and their formal or informal caregiver. In doing so, this Thesis provides the rapidly developing field of social technology with valuable knowledge relevant to current dominant discourses in tertiary public health and dementia caregiving. The knowledge provided in this dissertation can inform and guide system developers of social technology, formal and informal caregivers, long-term care facility managers and policymakers on how technological solutions may be utilised to safeguard social health through facilitated social participation and caregiving relationship sustenance. Finally, this body of work contributes to knowledge by using a relationship-centred approach that considers both care recipient and caregiver and advocates for future technology-driven psychosocial interventions to focus on caregiving dyads as a unit of attention.

Chapter Three. Research Questions

3.1 Overarching Aim and Objectives of this Thesis

The overarching aim of this cumulative dissertation is to explore the potential of technology to support dyadic relationships in dementia caregiving through social participation and enrichment for both dyad members.

The doctoral thesis has the following five objectives:

Objective one: *To analyse and synthesise, on the basis of the body of literature available, technology-driven social interventions for PLWD and their (in)formal caregiver to enhance communication and interaction, thereby potentially improving the quality of their dyadic relationship.*
To address the gap in the literature regarding the optimal nature of technological solutions to facilitate dyadic social interaction, it is necessary to establish what evidence is currently available regarding how technology might serve as a communication aid and interaction support. This objective was achieved in *Paper I* through a systematic literature review of technology that aims to support social health challenges and requirements in a dementia caregiving context.

Objective two: *To assess the efforts put in place to safeguard the social health of nursing home residents with dementia during the COVID-19 pandemic using technology, as well as explore barriers and facilitators in using social technology to promote social participation for this patient group.*
With the limited knowledge we have on the multiple impacts of the global pandemic on dementia caregiving, it was necessary to explore how measures against COVID-19 have influenced residents living with dementia in terms of social health, and how their formal caregivers safeguarded this health domain by means of technology to promote social participation. Furthermore, formal caregivers' experiences and opinions on strategies to promote the use of social technology to promote social participation in residents with dementia were sought. Taking on the perspective of those who provide professional care to people with a severe stage of dementia, *Paper II* reports on cross-sectional data collected in a national online survey in Germany during the second wave of the COVID-19 pandemic.

Objective three: *To assess how the COVID-19 pandemic has impacted the social participation and dyadic interaction of community-dwelling dementia caregiving dyads, as well as explore how dyads use technology in everyday life and their motivation for participating in a social technology intervention.*
While *Paper II* revolves around social participation during COVID-19 using technology in an institutional setting, *Paper III* takes a closer look at the community-based setting. Here, PLWD and their family caregivers also experienced social isolation, but under completely different circumstances. The COVID-19 pandemic provided unprecedented times to conduct empirical research including a psychosocial intervention. It was therefore necessary to explore how measures against COVID-19 have influenced the social health of community-dwelling dementia caregiving dyads and their perspectives on using social technology to

mitigate their extreme isolation. This objective is addressed in *Paper III,* which describes a pilot case study nested in a larger feasibility trial, where semi-structured interviews conducted at the baseline of our feasibility study allowed us to explore how our study participants have been affected by the COVID-19 restrictions and their motivation to try novel technology.

Objective four: *To evaluate a technology-supported activation system, I-CARE, specifically designed for PLWD to use in tandem with their caregiver in terms of usability, potential impacts and exploring barriers and facilitators to the independent use of this technology in a home-based setting*.
Currently, little is known whether tablet-based technology can support social participation and relationship sustenance among community-dwelling dementia caregiving dyads. To address this gap in knowledge requires an empirical study. By investigating the feasibility and impacts of using application-based technology such as the one presented in this doctoral thesis, existing care structures can be optimised through tertiary prevention and health promotion among community-dwelling PLWD and their caregivers. This objective is addressed in *Paper IV*, reporting on a feasibility study that investigated the effects and usability of I-CARE on social health aspects of community-dwelling dementia caregiving dyads.

Objective five: *To broaden the understanding and to classify beyond technological solutions, on the basis of the body of literature available, psychosocial intervention components that may contribute to enrichment in dementia caregiving dyads*.
In order to understand how relationships may be sustained or improved through enriching experiences for both caregiver and care recipient – regardless of the relationship nature – it is necessary to take a step back from focusing on the outcomes of interventions, and rather look into the intervention components themselves in their contribution to enrichment. To achieve this objective, the theoretical model of enrichment was operationalised and extended to include formal and informal relationships in dementia caregiving. The final paper comprising this dissertation, *Paper V,* is therefore a scoping review reporting on how this operationalised definition was used to structure the search, mapping and synthesis of data to explore what intervention components may contribute to enriching dyadic caregiving relationships in dementia.

Chapter Four. Methodology

In this chapter, the methodological approach in the five individual papers (Section 4.1, Section 4.2, Section 4.3, Section 4.4 and Section 4.5) comprising this cumulative dissertation is summarized. This chapter also outlines ethical considerations and data protection aspects of the empirical studies conducted (*Paper III-V*) (Section 4.6). Appendix A lists all individual papers and their corresponding URLs.

4.1. Study Design of *Paper I*

Paper I is a systematic literature review [156] of technology-driven solutions for PLWD and their caregiver to enhance communication and facilitate positive social interactions. A search of three electronic databases relevant to the scope of the review was conducted using a search strategy developed based on key identified papers. The search strategy was thereafter updated and revised in collaboration with the second author. The search strategy was thereafter applied to the three databases (PubMed, CINAHL and PsychINFO) and titles and abstracts were screened independently by the first and second authors in March and May of 2020. Peer-reviewed papers (published in English between 2010-2019) describing an intervention conducted with PLWD as the primary target group, using some form of technology focusing on social interaction and/or communication support for PLWD and their caregiver were included. Any discrepancies were discussed until consensus was achieved, and any remaining conflicts would have been solved by the third author. This step was, however, not necessary as full consensus was achieved. Data on citation details, technological devices, study design, outcome measures, instruments and key findings were extracted.

A critical appraisal of the included studies was conducted using the Mixed-Methods Appraisal Tools (MMAT) checklist [157]. The MMAT checklist enables researchers to assess the methodological quality of quantitative, qualitative and mixed-methods research using one combined tool. Although the MMAT allows for an appraisal of the methodological quality of studies with diverse designs, a well-known limitation is its reductive design when appraising mixed-methods studies; the overall score cannot exceed the lowest score of the qualitative or quantitative component, meaning that even with a 100 % score on the quantitative component a 40 % score on the qualitative component will result in an overall 40 % score. Nevertheless, the MMAT is a well-known and widely used appraisal tool in systematic literature reviews including diverse study designs, leading to the tool being deemed as appropriate to assess the methodological quality of the included papers. The systematic literature review resulted in a comprehensive overview of existing technologies used in the area of social health and dyadic relationships in dementia caregiving, as well as four key areas of impacts of facilitated social interaction for this dissertation, which contributed to the development of the interview guides used in *Paper III* and *Paper IV,* as well as informing the development of questionnaire items in *Paper II.*

4.2. Study Design of *Paper II*

The second paper reports on a cross-sectional study analysing data from a follow-up questionnaire included in a larger national online survey conducted in Germany during the second wave of the pandemic. Formal caregiving settings including nursing homes, outpatient and Day Centre facilities were surveyed focusing on structural characteristics, the occurrence of SARS-CoV-2, and the effects of the pandemic in terms of staffing, equipment and changed work processes and communication structures [158, 159].
The survey link was circulated via email among facility leaders and directors of nursing to an opportunity sample of 8187 nursing homes in Germany from January 12th to February 7th, 2021. The survey was also advertised through contacts of the study team to advocacy groups and provider associations. Potential participants were provided with an information letter explaining the study and eligibility criteria. This also included a cover letter where employees from the management level (directors of nursing, managing directors, quality management officers and nursing staff acting as ward managers) were invited to participate. The survey questions were generated from internal project literature reviews and preliminary work by the study team. The online survey was conducted using EFS Survey (Questback GmbH, Köln, Germany, 2019) and the response time was approximately 20 minutes.

The survey items subjected to analysis included both closed-ended and open-ended (free-text format) questions. Facilities' structural characteristics and lab-confirmed cases of SARS-CoV-2 were collected, as well as questions on the observed effects of the pandemic on nursing home residents with dementia, such as Behavioural and Psychological Symptoms in Dementia (BPSD) and increased use of pharmaceutical therapy. The survey also investigated efforts put in place to maintain social participation for nursing home residents with dementia, such as access to social activities, special visitation access and the establishment of procedures to use social technology. Training provided for staff to implement and use technology in the facilities was also surveyed. Finally, survey respondents could also make recommendations in free-text fields of requirements necessary to enable care recipients to use technology to promote social participation.

In the data analysis phase, responses from nursing homes were included in the analysis, with all other facility types, or responses with missing information on care service or facility type excluded. In the case of missing data for the remaining responses, the facility was excluded from the evaluation for this item only. The evaluation was carried out descriptively using relative frequencies of valid responses, mean values and chi-square independence tests with nominal significance level $\alpha = 0.05$. The free-text responses were subjected to an inductive thematic analysis approach according to the thematic analysis guidelines described by Braun and Clarke [160]. As the online survey was conducted in German, results were initially compiled in German and then translated to English by the first author, validated by a third-party German native speaker. The software tool STATA version 12 (StataCorp LP, College Station, TX, USA) was utilised for the statistical analysis, while the thematic analysis was performed using NVivo version 12 (QSR International Pty Ltd., Melbourne, Australia, 2020).

4.3. Study Design of *Paper III*

Paper III reports an empirical study conducted with community-dwelling dementia caregiving dyads, encompassing a pilot case study nested within the feasibility trial reported in *Paper IV.* The study design of these two papers is therefore closely aligned, although they differed in their objectives and area of focus.
The case study [161] reported on in *Paper III* was based on semi-structured in-depth interviews with the first three dyads that enrolled in the feasibility study of the trialled technology, I-CARE (described in Section 4.4). The three first dyads were recruited in the period of December 2020 to March 2021 through collaboration partners such as Day Centres, support groups, and the local Dementia Information and Coordination Centre (DIKS) in the vicinity of Bremen, Germany. Eligible participants were community-dwelling dementia caregiving dyads, the care recipient having received a formal diagnosis of dementia, and the informal caregiver either cohabiting with the care recipient or visiting at least twice per week, on average. For the PLWD, no form or stage of dementia was excluded. Participants were excluded from the study for reasons including: participating in another intervention trial, being bedridden or heavily immobilized, deafness or having severe hearing impairment, blindness or having severe visual impairment, or being diagnosed with schizophrenia or having a substance addiction.

The collaboration partners reached out to clients fitting the eligibility criteria who might be interested in participating in the intervention, providing them with the contact information of the research team, or alternatively, conveying the participants' contact information (with their consent) so that the research team could contact them directly. Dyads expressing an interest in participating in the study received comprehensive written and verbal information about the goals of the intervention, including eligibility criteria, the nature of the intervention, data collection procedures, and written consent forms. Dyads were thereafter given time to consider whether they still wanted to participate. Before enrolling in the study, all participants needed to sign a written consent form. During the baseline measurements, upon which the case study is based, dyads also received a digital tablet with the I-CARE system pre-installed (described in Section 4.4).

As a part of the baseline data collection, participant characteristics were recorded, including age, gender, number of children, and the estimated number of hours of care provided by the informal caregiver. In order to get a sense of the stage of dementia in the participating care recipients, the Functional Assessment Staging Tool (FAST; [162]) was also employed. FAST is a functional scale designed to allow caregivers to chart the decline of PLWD in seven functional disability stages, each assessing clinical descriptions of common abilities, including memory capabilities, personal hygiene, and taking care of oneself (e.g., dressing or eating). This function hierarchy has been found to be related to dementia-related cognitive decline [163]. The assessment was done by the informal caregiver using the FAST questionnaire as a proxy rating of the care recipient's functioning and might therefore differ from ratings by caregivers with a medical background (e.g. nurse or general practitioner). A semi-structured interview was conducted with each of the three caregiving dyads at baseline before they enrolled in the I-CARE intervention, conducted in German by a trained research assistant with experience in qualitative and quantitative research methods.

The audio-recorded baseline interviews were transcribed verbatim and translated from German to English by the research assistant (a German native speaker), before being subjected to an inductive thematic analysis according to the thematic analysis guidelines developed by Braun and Clarke [160]. This included the first and last author reading the transcripts multiple times to get familiar with the data before independently coding features of the data collating the codes and initial themes. Thereafter, these were discussed, reviewed, and revised at the level of the individual coded extracts and the full dataset by sorting the codes, transferring codes under similar sub-themes or collapsing sub-themes. The preliminary themes were refined and named collaboratively before being discussed between all authors to develop and modify them, achieving a consensus. The software NVivo version 12 (QSR International Pty Ltd., 2020) was used to facilitate the data's systematic organisation and analysis.

4.4. Study Design of *Paper IV*

The fourth paper encompassed in this cumulative dissertation reports on the feasibility study of our trialled novel technical device, I-CARE. The study was conducted following a mixed-methods approach, using a single group pre/post-test with follow-up design. As the overarching aim of this body of work is to explore the potential of technology to support social participation in PLWD and dyadic relationships in dementia caregiving, the study in *Paper IV* aimed to support enriching experiences in caregiving through shared moments that are meaningful to both dyad members using a digital device. The model of enrichment processes in family caregiving (EPC; outlined in Chapter Two) by Cartwright and colleagues [105] was therefore a central pillar in the development and design of the study in *Paper IV.*

The trialled technology, I-CARE, is a tablet-based activation system specifically designed to activate PLWD in social interactions together with a tandem partner [164-166], which in the purpose of the study was their family caregiver. The tablet encompasses a wide array of activities, including image galleries, videos, short stories, proverbs, quizzes and games. The activities are of different complexities and difficulty levels, which makes the system I-CARE suitable for most ages, types and stages of dementia. I-CARE also tracks feedback to estimate which content is most engaging to the PLWD, which feeds into a recommender system tailoring the content as it learns about the user. At the beginning of any I-CARE-supported session, the system asks about the daily well-being of the PLWD using a smiley rating scale (positive, neutral, negative). After this assessment, the recommender system suggests four activities based on user information such as age, previous occupation and interests, as well as ratings by the user from previous use. After each activity, the system asks the PLWD to rate the activity, again using a smiley rating scale, before the system returns to the content overview with new recommendations. The caregiving dyads can also choose content using the system's search function or activity history. The dyads can at any point decide whether to continue with another activity or cancel an ongoing one.

The I-CARE intervention recruitment and data collection was conducted between December 2020 and December 2021; the recruitment strategy and eligibility criteria are outlined in Section 4.3. In addition to assessing the impacts of the dyadic activities encompassed in I-CARE, the feasibility of the system was also evaluated in terms of usability issues such as usefulness and user-friendliness. The usability of I-CARE was explored in the post-intervention semi-structured interviews. The interview guide also contained questions exploring the impact of I-CARE sessions and possible barriers and facilitators of using I-CARE independently at home. As in the study reported in *Paper III,* the interviews were conducted in the participants' homes by a trained research assistant, audio-recorded and transcribed verbatim. The impacts on the participating dyads of using the tablet together were also assessed quantitatively using standardised internationally validated measurement instruments. The assessed outcome measures included caregiver burden for the informal caregiver, quality of life for both dyad members, and the dyadic relationship quality. The baseline assessments and participant characteristics collected are outlined in Section 4.3.
In the data analysis phase, descriptive statistics were used, and average differences in the reported outcomes between baseline (t0) and post-intervention intervention (t1); and between post-intervention (t1) and at four-week follow-up (t2) were calculated. The differences in scores between baseline and post-intervention and between post-intervention and follow-up were assessed using the paired t-test assessment. The small sample size resulted in p-values being approached in an exploratory manner to identify which outcomes may be worth investigating in a future, large-scale study – and the p-values of < .05 do not infer statistical significance. As with *Paper II,* the statistical was conducted using the software tool STATA version 12 (StataCorp LP, College Station, TX, USA).

The post-intervention interviews were analysed using the same approach as outlined in *Paper III.* The first and second authors again independently coded features of the data before collating the codes and initial themes. The main themes and subthemes were named and refined collaboratively through joint discussions, reviews and revisions, and all three authors approved the final overarching themes and subthemes. Questions relating to the usability of I-CARE were collaboratively analysed and organised in terms of participants' reflections on usefulness and user-friendliness, guided by the work of Lund and colleagues [167] on usability assessments. As with *Paper II* and *III,* the qualitative component was analysed using NVivo version 12 (QSR International Pty Ltd., Melbourne, Australia, 2020).

4.5. Study Design of *Paper V*

The fifth and final paper encompassed in this dissertation lifted the focus up from technology-driven solutions to support social participation and took on a broader perspective of the role of dyadic enrichment in social health. Because the purpose of the study reported in *Paper V* was to scope and present an overview of psychosocial interventions promoting enrichment in dyadic relationships in dementia caregiving relationships, a scoping review methodology [168] was deemed appropriate. The Preferred Reporting Items for Systematic Reviews and Meta-analysis Extension for Scoping Reviews (PRISMA-ScR) [169] served as the framework for this scoping review, which was informed by the Joanna Briggs Institute's (JBI) approach to conducting and reporting the scoping review [170]. To maximize the specificity and sensitivity of the search strategy, an initial list (developed based on prior review of relevant literature and pilot search) of search terms was refined and further developed in consultation with an expert research librarian at the University of Galway, before being applied to five electronic databases in March 2022: MEDLINE via Ovid, CINAHL, AgeLine, Cochrane Library, and PsycINFO via Ovid. Titles and abstracts were screened against the inclusion criteria independently by two researchers, with a third settling any discrepancies. Included were qualitative, quantitative or mixed-methods primary research studies published in English, describing psychosocial interventions targeting caregiving dyads consisting of PLWD and their caregiver(s), where intervention components could be identified as falling in under one of the three core elements of the theoretical model of enrichment (described in Section 2.5). Psychosocial interventions have not systematically been applied to the concept of enrichment in caregiving, less so in dementia research. To ensure consistent inclusion of relevant studies, the three core elements in the concept of enrichment (as developed by Cartwright et al. [105]) were therefore first operationalised and contextualized to caregiving relationships (elaborated in detail in *Paper V*). The operationalisation and contextualisation of the three enrichment core elements were informed by the empirical findings in *Paper III* and *IV*, as well as the conceptual framework of social health in dementia research and caregiving, developed by the INTERDEM Social Health Taskforce [31, 32, 81, 171, 172].

For the data extraction, the research team created a standard charting form in Microsoft Excel. Authors, publication year, the nation in which the study was conducted, study design, intervention characteristics, caregiving setting, type of caregiving relationship (formal/informal), and implementation/delivery method were all extracted to create a detailed description of the included psychosocial interventions. To ensure consistency in data extraction, the charting sheet was discussed among the researchers before they independently piloted the sheet using 20 % of the included studies. The remaining 80 % was thereafter charted by the first author, verified by the second. Thereafter, the first author deductively coded the extracted data by mapping identified intervention components onto the three core elements, verified by the second author. Any disagreements were discussed until consensus was achieved. Finally, the identified components were grouped within each core element to identify categories of intervention components that may contribute to enrichment in dementia caregiving relationships. These categories were discussed among all authors.

4.6. Data protection and ethical aspects

Paper II

Due to the precarious circumstances of the COVID-19 pandemic, the full anonymity of survey participants, and the focus of the survey laying at the organizational level, an ethics committee was not consulted in the preparation of the second paper encompassed in this thesis. However, a data protection concept was coordinated with the data protection officer of the University of Bremen. Potential participants were provided in advance with an information letter explaining the study and an explanation of data protection. All participants had to agree to the data protection statement and consent to participate in the study. No personal data assignable to individual vulnerable persons or residents were collected.

Paper III and *IV*

The studies reported on in *Paper III* and I*V* were planned, conducted and evaluated according to the existing capacities in accordance with the principles of Good Clinical Practice (ICH-GCP) and the Declaration of Helsinki. The ethical application and data protection protocol underlying the studies reported on in the third and fourth papers were subjected to the supervision of the data protection officer at the University of Bremen. The studies received ethical approval from the Deutsche Gesellschaft für Pflegewissenschaft e.V (DGP) in October 2020.

In order to implement the requirements of Art. 5 EU-DS GVO, all research team members involved were bound by data secrecy. All persons involved in the studies were subject to the obligations of confidentiality according to § 203 (2) No. 6 StGB. Pseudonymisation strategies for data processing were used within the research team wherever possible. However, due to the nature of the data collection, participants were not anonymous for the research team. Participants' contact details and signed informed consent sheets were kept separately from the collected data and were password protected and only accessible to the study team. In the transcription of the audio files, the participants were given a pseudonym known only to the study team so that, if necessary, statements by individual persons could be deleted from the data until the study results were published in case of participant withdrawal. The key list with the assigned pseudonyms was kept separately from the audio files, transcripts and evaluation files, password protected and only accessible to the study team.

The studies reported on in *Paper III* and *Paper IV* collected and analysed personal data of a population group that is considered vulnerable, requiring careful consideration of needs to be taken so that the health and well-being of both dyad members are ensured. The emphasis on *informed* in the term 'informed consent' must be at the forefront of any interventions including people living with cognitive impairments or otherwise falling under the category of a vulnerable population group. Special measures were therefore taken to ensure full transparency in the studies reported in *Paper III* and *Paper IV.* Transparency in this case refers to the availability of comprehensible information to anyone implementing involved with the recruitment or participation in the studies, including collaboration partners supporting recruitment efforts, informal caregivers and the PLWD as far as possible. All stakeholders involved were provided with information about the nature and purpose of all data collected, as well as their possibility to withdraw from the study at any point in time. PLWD have the right to information about things that affect them, presented in a way that is as easy to understand as possible [173]. In order to ensure informed consent from the participants with dementia, the provided information was adapted to a dementia context; the studies' purposes, the trialled technology's objectives, functions, and data collection from individuals were therefore explained to the extent possible according to the capacity of PLWD and their participating informal caregivers [174]. This included adapting the language, style, length, and format of the written information as well as providing the same information verbally during initial telephone conversations and during the debriefing meeting before the participants decided on whether they wanted to participate.

Chapter Five. Findings – a short presentation of the individual works

5.1. Technology facilitating social interactions between people with dementia and their caregivers

We already know that technology allows individuals to connect remotely worldwide, but less attention has been directed at technology supporting individuals to connect on a deeper, interpersonal level while sitting side-by-side. Technology directed at providing support in social interactions between PLWD and their caregivers is still in its infancy. Nevertheless, there is an existing potential in utilising technological devices as a third-party participant in social interactions between PLWD and their formal or informal caregivers, as emerging research suggests that technological solutions can to a certain extent mitigate the consequences of dementia on speaking abilities and impaired memory. This, in turn, can support people living with dementia and their caregivers to sustain relationships by finding new ways to communicate and socially interact. In *Paper I,* the way in which technology may support and enhance dyadic relationships in a dementia caregiving context was explored by means of a systematic literature review. Specifically, technology-driven interventions that could facilitate positive social interactions between PLWD and their caregivers – regardless of the caregiving setting – were investigated.

The systematic literature review includes 18 studies, revealing that the most employed technology to facilitate positive dyadic social interactions was tablet computers (n = 7 studies), social robots (n = 5 studies) and computer systems (n = 4 studies). The two final studies included for review investigated the psychosocial impacts of well-familiar and novel technology, respectively. The former used low-tech DVD technology to create Multimedia Biographies (MBs) to stimulate social interactions between PLWD and their family caregivers, while the latter used 3D-printing technology to create individualised reminiscence objects for PLWD in an LTC facility setting. Regardless of novelty or format, it was found that these technologies could support social interactions in a dementia caregiving context through four distinct mechanisms: i) breaking the ice, by providing a conversational platform giving PWLD and their caregiver(s) a gateway to initiate dialogue; ii) facilitating interactions in terms of increased communication frequency and duration by encouraging more involvement in the dyad; iii) better understanding of PLWD through devices that stimulate the sharing of memories; and iv) reduced pressure for the conversation partner to uphold the conversation by making the communication more reciprocal in the dyad. These benefits generated positive experiences for the dyad members, which could ultimately enhance their relationship.

Nevertheless, when appraising the quality of the evidence, it became clear that research in this area is still in an explorative phase. Although all of the purely qualitative studies reached an 80 % score on the Mixed Methods Appraisal tool (MMAT), two of the three purely quantitative studies reached only a 40 % score. Of the mixed-methods studies, only one reached a 100 % MMAT score. Five of the nine mixed-methods studies included had a strong qualitative component, with a weaker quantitative component, resulting in an overall lower MMAT score application. Another reason for a low overall MMAT score included poor integration of qualitative and quantitative components, which was the case for two of the included studies. It was clear that the included quantitative studies were of a weak methodological quality, which was observed in the mixed-methods studies as well. Finally, the results revealed that there are few existing standardized measurement instruments aiming specifically to measure communication and social interaction in a dementia context. Although several of the included studies measured QoL and well-being, it seems that the instruments used do not have the sensitivity to capture outcomes such as dyadic enrichment, conversation quality and positive experiences in social interactions. These dimensions were captured more in detail through qualitative study components, such as semi-structured interviews, which allowed room for a deeper exploration of study participants' experiences, thoughts and reflections.

5.2. COVID-19 restrictions, social health and the role of technology to promote social participation in nursing home residents with dementia

The full impacts and consequences of the COVID-19 pandemic for people living with dementia (PLWD) and their caregivers are still emerging, but one thing is clear – society's preparedness to safeguard the social health of this population was insufficient. Especially PLWD in institutional settings were vulnerable to the extreme social isolation that followed the preventive measures against COVID-19. Efforts to safeguard the social health of PLWD had to be put aside in consideration of safeguarding the physical health of care recipients and their caregivers by minimising the risk of exposure and contraction of SARS-CoV-2. Social isolation has been found to contribute to the worsening of Behavioural and Psychological Symptoms in Dementia (BPSD), which may lead to increased use of pharmaceutical therapy. This is concerning, as pharmaceutical therapy has been found to have low effects on BPSD with rather large side effects. With limited room for in-person social interactions, technology might be a feasible strategy to mitigate social isolation among nursing home residents with dementia during times of social isolation.

Paper II describes the results from a study based on cross-sectional data from a follow-up questionnaire as a part of the larger national online survey conducted among representatives of German nursing homes during the second wave of the COVID-19 pandemic. In addition to surveying structural characteristics of the nursing homes and lab-confirmed cases of COVID-19, there were multiple sets of questions on the observed effects of the pandemic on nursing home residents with dementia, including increased instances of BPSD and the use of pharmaceutical therapy. Respondents were also asked about efforts in maintaining social participation for these residents through social activities and the use of technological tools, as well as training provided for the nursing home staff to implement and use such technology. Finally, participants could also make recommendations of requirements necessary to enable the uptake of technology to promote social participation.

Four hundred-and-seventeen valid individual responses (around five per cent of the invited facilities) were received, with most nursing home representatives working as facility managers or directors of nursing. 212 (52.7%) of the nursing homes participating in the survey reported lab-confirmed COVID-19 cases among residents, with 69.9% of respondents reporting lab-confirmed COVID-19 cases among their staff. The responses indicated an overall low increase in pharmaceutical therapy for nursing home residents with dementia, which was observed in less than six per cent of the facilities. However, a large proportion of the respondents saw an increase in at least one BPSD, where depression and anxiety were most frequently reported (38.9 % and 38.6 % of respondents, respectively). Appetite loss (24.1 %), aggression (16.9 %) and wandering (16.9 %) were also reportedly observed to have increased. More than a third of the respondents reported that social activities for nursing home residents with dementia were cancelled during the COVID-19 pandemic. This was correlated with whether the nursing homes had lab-confirmed COVID-19 cases among residents ($\chi^2 = 7.69$; $p = .021$) or staff ($\chi^2 = 9.98$; $p = .007$), as well as staff shortages of 5 % and up ($\chi^2 = 13.09$; $p < .001$). No correlation was found between the cancellation of social activities and nursing home structural characteristics (i.e., private/public/non-profit provider or having a special dementia care contract).

Less than seven per cent of the surveyed nursing homes had established procedures for using technology to promote social participation for their residents with dementia. Additionally, the vast majority had received no training in using technology to promote social participation among their care recipients. Of the respondents who reported that *some* training had been provided, 32 % had less than two hours of training, while six per cent had received up to half a day of training in the matter. Nevertheless, 72.8 % reported additional opportunities for residents with dementia to connect with friends/family using technology. In the qualitative component, requirements to promote social participation using technology was identified at the micro-, meso- and macro level. Requirements concerning the technology in itself permeated all three levels. Within the micro-level, free-text comments from respondents could be grouped into three main categories: i) user capabilities; ii) user willingness; and iii) family support. Comments related to user capabilities expressed concern about not only the cognition of PWLD as users but also their advanced age, with respondents being pessimistic about older adults being able to use technology independently. Closely related, user willingness encompassed respondents expressing concern about their care recipients being quickly overwhelmed when operating technological devices. Therefore, family members were perceived as key to actively participating with their relatives with healthcare needs in acquiring, getting familiar with, and using technology.

At the meso-level, organisational requirements could be divided into three parts: i) technical support; ii) training; and iii) sufficient resources. Technical support was expressed by respondents to be important not only during the implementation phase but also to be available continuously, with contact personnel exclusively handling technical issues. Up-to-

date education in technological solutions for healthcare providers was described as essential to raise awareness of technological possibilities and to equip them with pedagogical training to support technology use. The final category revolved around time and staff. Several collected comments expressed frustration over the inadequate time and personnel available to incorporate technology to effectively benefit providers and care recipients.
At the macro level, the main requirements identified were related to i) cost coverage; and ii) network infrastructure. The issue of cost coverage was a recurring theme, where respondents urged for acquisition costs to be covered by insurance schemes or funders. However, many respondents felt resigned by the poor internet broadband coverage in Germany, hindering practical technology use among caregivers and care recipients, especially in rural areas.

The final category of requirements reached across all three levels and was found with the technology itself. These requirements were predominantly related to i) availability; and ii) user-friendliness. Network infrastructure can also be regarded as a central requirement within the technology itself. Regarding availability, respondents emphasized the need for available hardware, software and internet to enable care recipients to establish connections with family, friends and healthcare providers. Proper internet connection opportunities within every household were a condition emphasized by respondents as frequently as required hardware. Technology-friendly healthcare provision necessitates user-friendly technology, and respondents urged simple usability and self-explanatory functions. Many recommended focused efforts to be put in place into the design in terms of a large display and few buttons, possibly even offering a voice assistant function, for technology to be appropriate for care recipients with dementia.

5.3. Social Isolation during the COVID-19 pandemic and the use of technology among community-dwelling dementia caregiving dyads

The extreme social isolation that followed the COVID-19 pandemic was present not only for care recipients in institutional settings but for community-dwelling caregiving dyads as well. The COVID-19 restrictions led to most non-essential services being closed, leaving many community-dwelling people with dementia and their family caregivers mostly confined at home, with few activities to engage in. With limited support available either from health and care services or from friends and family, social isolation may strain caregiving relationships and increase the burden placed on the family caregiver of PLWD. Social technology may mitigate some of the adverse effects of COVID-induced isolation, by either connecting users, or providing safe and engaging activities to do at home. As shown in *Paper I*, many existing technology-based social interventions have shown promise in engaging dementia caregiving dyads in meaningful activities, positively impacting social health, including social participation, relationship quality, and carer resilience. Closely related to the argument made in Section 5.2, there is reason to believe that community-dwelling dementia caregiving dyads also have been impacted by the COVID-19 pandemic and the following social isolation, but little research exists on this topic thus far. Additionally, it is crucial to understand the contextual factors that might influence any intervention in a specific setting. Therefore, *Paper III* reports on the preliminary findings from the intervention study conducted as a part of this doctoral project, reporting on the experiences of three caregiving dyads from living under extreme social isolation, their usage of social technology as well as their perceived barriers and facilitators in using social technology when living with dementia.

All three dyads in *Paper III* consisted of a husband with dementia and his wife providing care. The stage of dementia among the participants ranged from mild, moderate-severe and severe. Wives and husbands' age ranged from 57 to 83 and 58 to 85 years old, respectively. The youngest dyad was the most familiar with technology, which was a vital source of support for the wife, whose husband lived with severe dementia. She was an experienced user of videoconferencing tools to stay in touch with her social network, as well as support groups. The oldest dyad had no experience with using technology for social purposes, but on the other hand, they were the only participants who utilised assistive technology to support independent living. They did not receive any respite services, nor were they interested in support groups. The third dyad had some experience with social technology to reminisce together, and the wife telephoned and emailing with social support groups for relatives of PLWD.

The extent to which the three dyads had to adjust to the COVID-19 restrictions seemed to be influenced by two main factors, namely, how socially active the dyad had been within their social support networks, and their familiarity with social technology. When analysing the transcribed baseline interviews from the three participating dementia caregiving dyads, two themes and seven sub-themes emerged. The first overarching theme, 'living with dementia during COVID-19' was identified based on the differences in the experiences reported by the dyads. Within this main theme, three subthemes could be distinguished: i) social and leisure activities; ii) dyadic interaction; and iii) adjusting as a caregiver. Looking at the first subtheme, it was clear that, the dyads' perception of the impact of COVID-19 on their lives could, to a certain extent, be linked to their caregiving situation—such as the stage of dementia and the availability of supportive networks. However, none of the dyads meant their dyadic interactions had been influenced by the pandemic. Their relationship was maintained by sticking to their daily routines and adjusting them as needed, given the ongoing restrictions. Although the dyads' interactions remained as before the outbreak, the framework within which they communicated had changed due to the restrictions, influencing how the dyads coped with being isolated together. Finally, within the third subtheme, the interviews revealed that the caregiver in each dyad was still adjusting to their role, the emerging strain the dementia diagnosis entailed, and their development of coping strategies. With the COVID-19 outbreak, they had to further adjust to the caregiving role in a new context, taking on an even larger responsibility for their spouse and their own psychosocial well-being.

The second overarching theme, 'the role of technology in a pandemic' was identified due to the role of technology in promoting active participation in daily life being a central part of the discussions. The four subthemes falling under this second main theme included i) facilitating social activities; ii) facilitating dementia care-related activities; iii) barriers and facilitators in using social technology; and iv) the underlying motivation to invite technology into dyadic interactions.

The first two identified subthemes showed that technology did not only play a role in facilitating social activities but also dementia care-related activities for the participants. The dyads who managed to make use of for instance videoconferences, found support either by staying connected with family and friends, or by participating in virtual support groups. Those who only used e-mail or telephone for the same purposes felt this was not sufficient to mitigate their isolation. Several barriers and facilitators to using social technology came up during the interviews, and are all closely related to those identified in *Paper II.* The three dyads expressed barriers and facilitators as related to tech literacy, user willingness, and sufficient support. Finally, the dyads' motivations for inviting technology into their social interactions, differed between the three couples including i) keeping up with developments; ii) doing something new together; and iii) finding conversation support.

5.4. Sustaining togetherness in dementia caregiving dyads using novel technology

The fourth paper of this cumulative dissertation reports on the feasibility trial of I-CARE, a tablet-based activation system specifically developed for PLWD to use in tandem together with a caregiver (elaborated in Section 4.4). Eighteen participants (i.e., nine dyads consisting of a PLWD and their family caregiver) enrolled in the I-CARE intervention, where all except one dyad (two sisters) had a spousal relationship. All care recipients were formally diagnosed with dementia, with the severity ranging from mild to severe. The participants with dementia had a mean age of 77 (range 58–89; SD 9.47) while the mean age was 72 for caregivers (range 57–87; SD 12.04). Eighty-nine per cent of the caregivers were female, with 78 % of care recipients being male. I-CARE was perceived as useful to all participants except for two husbands with dementia, who did not care for the technical nature of the I-CARE activities. Nevertheless, I-CARE seemed to be a feasible tool to facilitate enrichment in caregiving dyads by providing a common platform for joint attention. Most of the participants perceived I-CARE as user-friendly in terms of being easy to initiate and conclude. However, dyads living with a mild stage of dementia found the activities too simple, while dyads living with more severe stages viewed the activities as too complicated. Additionally, there are still bugs and technical errors contained in the system which require fixing in order to further improve user-friendliness. These technical difficulties were a major concern to the study team, which due to the pandemic could not provide continuous technical support, but were dependent on participants reporting them. To further complicate matters, participants were reluctant to "be of bother" and would rather refrain from reporting errors until the next scheduled meeting.

When assessing the quantitative outcomes, a steady decline in QoL of both PLWD and their caregivers was observed. Interestingly enough, this decline was less steep during the I-

CARE intervention for PLWD compared to the follow-up period without the system, while the opposite was true for caregivers. Although p-values are approached in an explorative manner, this trend was only significant for the PLWD. Furthermore, PLWD consistently reported higher values for relationship quality than the caregivers, with results pointing to a non-significant increase in overall reported relationship quality in the intervention period, followed by a significant decrease in the follow-up period. This was the case for both dyad members. No significant changes were observed in caregiver burden.

Similar to the preliminary findings reported in *Paper III,* two overarching themes were identified in the qualitative component. 'The beneficial effects on the dyadic relationship' and 'technology requirements'. Within the first overarching theme, the effects of the I-CARE facilitated social sessions could be divided into four subthemes: i) enrichment in social interactions; ii) facilitating communication; iii) providing a shared activity; and iv) togetherness in the relationship. I-CARE was perceived as meaningful as the sessions stimulated the partner with dementia to actively participate. This was a pleasant discovery for some of the caregivers who otherwise had struggled with finding activities the dyad could do together. Additionally, I-CARE was perceived as helpful in aiding conversations by sparking discussions and introducing new topics to talk about. Non-verbal communication support was also observed in that participants with severe dementia nevertheless responded to their caregiver's comments. By serving as a point of joint attention, I-CARE provided a shared activity and something new to explore together. Charting unfamiliar territory provided a sense of mastery for some caregivers and PLWD alike. Finally, I-CARE contributed to a sense of sustained togetherness in several dyads, as they could be actively engaged as a pair.

The second overarching theme identified, 'Technology requirements', could be further divided into the two subthemes 'Barriers to overcome' and 'Facilitators to promote'. The first subtheme, 'barriers to overcome' could be divided into user-related barriers and technology-related barriers, as outlined in the usability issues of I-CARE. User-related barriers included both PLWD and their caregivers, with the cognitive capabilities of the care recipient with severe dementia being the main barrier to engaging with I-CARE, as well as their energy capacity on a given day. This influenced their motivation, which dictated the level of encouragement required from the caregiver. Caregivers' capacity to engage with I-CARE was therefore also influenced by their own energy level, but also available time and their familiarity with technology. However, limited tech literacy could to a certain extent be mitigated by tech interest including curiosity and willingness to explore novel technology. This was an important facilitator identified. Still, the most important facilitator by far was close and continuous, proactive tech support. Short video tutorials were provided as extra support to the participants, as well as instructions to reach out if they had any questions, regarding how small. However, the participating dyads were averse to reaching out for help, and it was clear that proactive, in-person technical assistance was key in giving especially the caregivers a sense of confidence to take on a role as a tandem partner and support their loved one with dementia while using I-CARE.

5.5. Psychosocial interventions promoting enrichment in dementia caregiving relationships

To create a more balanced understanding of dementia and a more dementia-friendly society, a need has been voiced, urging a shift of focus from symptoms and disability toward the capacity and potential of the person with dementia. The spearheaded efforts of the INTERDEM Social Health Taskforce contribute to this work, however, few conceptual models are taking on a positive discourse while simultaneously sufficiently including both PLWD and those who care for them. Chapter Two outlined the theoretical and empirical position of this cumulative dissertation, and advocated the importance of the uptake and development of a relationship-centred theoretical framework taking on a positive discourse in dementia research and caregiving. There is a potential in employing the theoretical framework of 'Enrichment'. However, although this model was developed back in 1994, it has not yet been applied in dementia research and practice. Furthermore, although the model takes on a relationship-centred approach, it does not include formal caregiving relationships. Therefore, in the first individual paper in this body of work, the core elements of enrichment were operationalised, broadened and conceptualised to a dementia caregiving context, across both formal and informal dyadic relationships. This process is elaborated in full in *Paper V*.

This operationalised concept of enrichment guided a scoping review, which charted the evidence of intervention components that may generate enrichment in psychosocial interventions for dementia caregiving dyads. The aim was to understand how to improve or maintain relationships through enriching experiences for both dyad members. The scoping review resulted in 34 studies, which were mainly directed at either supporting dyads to engage in shared activities (n = 22), or describing interventions revolving around carer education or training (n = 10). A third category, encompassing only two studies, contained elements contributing to enrichment by restructuring the caregiving framework around PWLD. Specifically, by either restructuring the physical environment surrounding the framework within which the caregiving dyad would interact or by changing the social aspects of the care provision of PLWD to support the caregivers to take more ownership in their role. By mapping intervention onto the three operationalised core elements of enrichment, categories of intervention components contributing to enrichment were identified.

Within the first core element, 'acquired symbolic meaning' four categories were identified: i) *core focus on dyadic relationships*, which specifically targeted improving or maintaining the dyadic relationship; ii) *supporting communication*, which revolved around dyadic communication support through tools or structured conversations; iii) *common platform for activity engagement*, by providing a point of joint attention; and iv) *socially oriented caregiving*, by shifting focus towards forming meaningful relationships, facilitating openness and engaging PLWD in social interactions. The second core element, 'performing activity', also distinguished four categories: i) *dementia-friendly activities*, which engaged both dyad members in social activities appropriate for a dementia context; ii) *enhancing dementia* *caregiving*, facilitated by supportive tools, restructuring of care provision or activity-based therapies; iii) *formal carer education and training*, which placed emphasis on providing optimised care through improved social interactions, awareness and person-centredness. The fourth category, *informal carer education and training,* focused more on adapting and adjusting to a dementia diagnosis through coping strategies, communication, skill acquisition and supportive tools. The final core element, 'fine tuning', encompassed three categories: i) *developing and/or specifying goals*, which revolved around supporting one or both dyad members to formulate and monitor individualised goals and identify their individual and collective strengths; ii) *emotional support*, to help dyads use the relationship as a source for coping, as well as becoming more familiar with common symptoms and behaviour in dementia; and iii) *adapting the environment*, in ways that supported the dyadic relationship and space for generating enrichment.

The scoping review described in *Paper V* found an important distinction in enrichment between formal and informal dyads: in formal caregiving relationships, interventions were mainly directed at changing the care provision in ways that shifted the focus from purely custodial care to caregiving with space for social interactions between the dyad members. Interventions targeting informal caregiving relationships were more directed at mitigating and circumventing some of the challenges that might follow a dementia diagnosis. In other words, enrichment in formal dyads seems to require dedicated space (such as protected time) to allow relationships to build and grow, while enrichment in informal dyadic relationships requires considerations of the dyad members' shared history and support in coping and managing changing relationship dynamics caused by dementia. Notably, communication support and skill acquisition seemed central in laying the groundwork for generating enrichment in the dyadic relationships, regardless of whether the relationship was of a formal or informal nature. The findings reported in *Paper V* show that taking on a relationship-centred approach using and extending a theoretical framework for enrichment may be a fruitful strategy to develop and promote psychosocial interventions supporting dyadic relationships in dementia caregiving.

5.6. Summary of central findings

Table 1 summarises the guiding research questions, methodology and the central findings of the five individual papers and embeds them in the overall context of this cumulative dissertation. With regard to the knowledge gap outlined in Section 2.7 and the overarching research question formulated in Chapter Three, the scope of the work presented in this thesis explored the potential of technology to support dyadic relationships in dementia caregiving through social participation and enrichment. In addition to the overarching research question formulated in this cumulative dissertation, five main objectives were outlined. Each objective was postulated and addressed in their respective peer-reviewed published paper. The key findings are summarised under each objective:

Objective one: To analyse and synthesise, on the basis of the body of literature available, technology-driven social interventions for PLWD and their (in)formal caregiver to enhance communication and interaction, thereby potentially improving the quality of their dyadic relationship. This objective was addressed in *Paper I* – a systematic literature review of technology that aims to support social health challenges in terms of communication and social interaction in a dementia caregiving context. The literature review demonstrated that:

- The most commonly used technologies to facilitate communication and social interactions in dementia caregiving were tablet computers, social robots and computer systems.
- Social technology used to promote positive social interaction contributed to positive outcomes related to: i) breaking the ice by initiating dialogue and serving as a conversational platform; ii) increasing interaction frequency and duration by encouraging more involvement between the conversation partners; iii) better understanding the person with dementia through reminiscence activities; and iv) reduce pressure on the conversation partner by making the communication more reciprocal. No adverse effects of using social technology in social interactions were reported in the studies included for review.
- Although social technology shows great potential in facilitating social interaction and communication in dementia caregiving, the findings show that research in this area is still in an explorative phase: small sample sizes, lack of control groups and rarely including follow-up periods indicate a dearth of high-quality studies examining social technology's effectiveness.
- The diversity in study methodologies and few standardised instruments indicate a need for further research to develop and validate new assessment tools for positive outcomes in social health. This research gap indicates a lack of attention to the relational dynamics in dementia caregiving, such as social interaction and dyadic communication.

Objective two: To assess the efforts put in place to safeguard the social health of nursing home residents with dementia during the COVID-19 pandemic using technology, as well as explore barriers and facilitators in using social technology to promote social participation for this patient group. The third objective took a closer look at the institutional setting and was addressed in *Paper II* of this thesis. Here, cross-sectional data collected in a national online survey circulated among German nursing homes during the second wave of the COVID-19 pandemic was analysed, revealing that:

- Technology-supported non-pharmaceutical strategies to promote social health among nursing home residents with dementia should be an integrated part of caregiving procedures
- Staff shortage of as little as five per cent was significantly correlated with social activities for PLWD being cancelled in German nursing homes.
- Less than half of the respondents included in our study indicated that they had received any form of training to use technological alternatives to facilitate social participation among these residents. Together with the low frequency of established

technology procedures, it seems that the actual use of social technology indicates the implementation of ad hoc solutions to safeguard the social health of residents with dementia.

- Therefore, technology should be incorporated as a standard resource to maintain social participation among PLWD. To ensure accessibility and availability of social technology for this patient group, prerequisites at the micro, meso and macro level must be addressed, as well as requirements identified in the technology itself.
- If the identified requirements are to be fulfilled, social health must be recognised on equal terms as the physical and mental health domains. Only then can technological solutions to promote social health be implemented successfully.

Objective three: To assess how the COVID-19 pandemic has impacted the social participation and dyadic interaction of community-dwelling dementia caregiving dyads, as well as explore how dyads use technology in everyday life and their motivation for participating in a social technology intervention. This aim was undertaken in *Paper III*, which described our pilot case study nested in the feasibility study encompassed in *Paper IV*, using baseline semi-structured interviews to explore how participants have been affected by the COVID-19 restrictions and their motivation to try novel technology. The case study revealed that:

- The impacts of the COVID-19 pandemic on community-dwelling caregiving dyads could be divided into two overarching themes: i) living with dementia during COVID-19 (subthemes: social and leisure activities, dyadic interactions, adjusting as caregiver); and ii) the role of technology in a pandemic (subthemes: facilitating social activities, facilitating dementia care-related activities, barriers and facilitators to using social technology, the underlying motivation to invite technology into interactions)
- Caregiving dyads who were socially active before the COVID-19 preventive measures and who managed to use social technology to facilitate and maintain their social engagement during the pandemic were less negatively impacted by the restrictions.
- Caregiving dyads differed in how COVID-19 restrictions impacted their lives and how they coped with dementia, revealing different motivations for wanting to invite technology into their social interactions. These motivations included the wish to try something new together, keeping up with technological developments and having conversation support in the dyadic interactions.
- Successful uptake of social technology is dependent on customizing it to the individual’s needs and conditions, necessitating efforts to tackle barriers that exist for older adults with or without dementia in using social technology.

Objective four: To evaluate a technology-supported activation system, I-CARE, specifically designed for PLWD to use in tandem with their caregiver in terms of usability, potential impacts and exploring barriers and facilitators to the independent use of this technology in a home-based setting. These objectives were addressed by the empirical study that is presented in *Paper IV*, reporting on a feasibility study that investigated the effects and usability of I-CARE on social health aspects of community-dwelling dementia caregiving dyads. The feasibility trial showed that:

- I-CARE is a viable tool to generate enriching experiences in caregiving dyads by serving as a point of joint attention. The system was found user-friendly by most participants by being easy to initiate and conclude without lengthy procedures.
- Although the outcome measures were assessed using p-values in an exploratory manner, positive trends were observed in the quality of life and relationship quality as rated by the PLWD; however, statistical inference cannot be made due to the small sample size. The positive trends were strengthened by the qualitative component, revealing beneficial effects of using I-CARE related to i) enrichment in social interactions; ii) facilitated communication; iii) having a shared activity and iv) relationship sustenance.
- I-CARE's design and back-end system need to be revised before further implementing and assessing the activation system. To ensure the successful uptake of I-CARE and similar systems in a home-based environment, it is crucial to have continuous proactive technical support over an extended period until users feel confident in using the system independently.
- Social technology aiming to facilitate social interactions needs to meet the dyad as a unit, with content adjusted for both dyad members.

<u>Objective five:</u> On the basis of the body of literature available, to broaden the understanding and to classify beyond technological solutions, psychosocial intervention components that may contribute to enrichment in dementia caregiving dyads. The fifth and final objective of this cumulative dissertation was achieved in *Paper V,* which reports on a scoping review of psychosocial interventions (technology-driven or otherwise) for dementia caregiving dyads contributing to enrichment and thereby sustaining or improving their relationship, regardless of the caregiver being formal or informal. The scoping review found that:

- Studies included for review mainly reported on psychosocial interventions that i) facilitated engagement in dyadic activities, ii) included training or education for caregivers, or iii) restructured the environment around care recipients with dementia.
- By charting psychosocial intervention components within the enrichment core elements, categories of intervention components that potentially contribute to enrichment were identified.
- Enriching activities can provide a vehicle to maintain or strengthen dyadic relationships and enhance positive outcomes for both caregiver and care recipient; however, few of the included studies directly aimed to support the dyadic relationship, and none of them explicitly focused on enrichment as a means to support the dyadic relationship.
- While informal caregiving interventions must consider the pre-existing relationship and offer assistance in coping and managing changing relationship dynamics when facilitating positive interactions, formal caregiving interventions may contribute to

enrichment by providing dedicated space for relationships to develop and grow through positive interactions. Communication support and skill acquisition in dementia caregiving seem to play a central part in laying the groundwork for generating enrichment in dyadic relationships.

- Regardless of technology-driven or otherwise, relationship-centred care approach should be utilised when developing and implementing psychosocial interventions in dementia, with the dyad as a unit of attention. This can be achieved by using and extending a theoretical framework for enrichment to develop and promote psychosocial interventions supporting dyadic relationships in dementia caregiving. The findings from this scoping review may inform the development and implementation of such interventions.

Table 1. Summary of the five individual works and embedding in the overall context

Guiding research question(s)	Methodology	Key findings	Embedding in the overall context
Technology facilitating social interactions between people with dementia and their caregivers			
What technology-driven solutions are used to prompt conversation, facilitate communication, and enhance social interaction between PLWD and their conversation partner? **How do the technological devices aid in achieving these outcomes for both members of the caregiving dyad?** **What methodologies are utilized to evaluate the**	• Systematic literature review. • Primary research (quantitative, qualitative or mixed-methods) describing an intervention, published in English. • Databases: PubMed, CINAHL, PsychINFO. • Two reviewers screening independently. • Critical appraisal: Mixed-Methods Appraisal Tool (MMAT).	• 18 studies included for review, with the majority of interventions including tablet computers (n =7), social robots (n=5) and computer systems (n=4). • The reviewed technologies were found to support social interactions in dementia caregiving dyads by: i) breaking the ice; ii) increased interaction; iii) better understanding of the person with dementia; and iv) reduced pressure for the conversation partner. • Few standardised measurement instruments sufficiently sensitive to capture social interaction and positive communication in a dementia caregiving context. • Critical appraisal using the MMAT revealed that quantitative studies on social health in dementia are weak in quality.	• Technology seems to have great potential as a third-party participant in social interactions in dementia, facilitating positive relationship gains for both care recipient, caregiver and the dyad as a unit of attention. • However, results show that relationship-centred dementia research utilising technology to potentially generate enrichment in caregiving relationship, is very much in its infancy. Not only in terms of novel technology, but also in standardised validated measurements sufficiently sensitive to measure positive social dyadic interactions. • Qualitative research is a valuable contributor where quantitative measurements fall short, in providing a deeper understanding of how technology may contribute to positive individual and shared relationship gains. • From the second individual work, several mechanisms through which technology may generate positive outcomes in dementia caregiving emerge for this dissertation, which to a large extent

effectiveness of these technologies?			informed the development of the interview topics guide and design of the intervention study reported in *Paper III* and *IV*. • The identified commonly used technologies in this individual work also informed the development of question items included in the survey reported on in *Paper II*.
COVID-19 restrictions, social health and the role of technology to promote social participation in nursing home residents with dementia			
Has there been an observable change in the clinical conditions of nursing home residents with dementia during the COVID-19 pandemic? **How did the COVID-19 pandemic impact the availability of social activities for nursing home residents with dementia?** **How has technology**	• Cross-sectional study based on online follow-up questionnaire nested in a larger online survey. • Multiple-choice survey items: structural characteristics, lab-confirmed cases of SARS-CoV-2, clinical outcomes for nursing home residents with dementia, efforts in maintaining social participation, technology employment, training in technology implementation. • Free-text survey items: requirements to	• 417 valid individual responses received (ca. 5 % of invited facilities) • 52.7 % and 69.9 % of respondents reported lab-confirmed COVID-19 cases among their residents and staff, respectively, since the outbreak. • < 6 % of respondents observed increased use of pharmaceutical therapy for residents with dementia. A large proportion observed an increase in at least one BPSD (e.g., 38.9 % and 38.6 % observed an increase in depression and anxiety, respectively). • 42.4 % experienced social activities for residents with dementia being cancelled, which was highly correlated with lab-confirmed COVID-19 cases and staff shortages. • < 7 % of respondents reported established procedures for employing social technology, and 50.7 % had not received any training in using it.	• Although the focus in this individual work was not on the relationship between caregiver and care recipient, it is important to understand the contextual influencers and challenges in using social technology, in the efforts to promote the use of technology to facilitate better caregiving relationships. • The findings reported in *Paper II* show that during and beyond the COVID-19 pandemic, technology-driven solutions to promote social health among nursing home residents with dementia should be integrated into caregiving procedures. • Looking at the enrichment model, the findings from this individual work may contribute to outlining antecedent factors influencing enrichment processes, such as the caregiving situation, which was of a highly unprecedented nature during the COVID-19 pandemic.

played a role in ensuring social participation for nursing home residents? **What barriers and facilitators exist for people in need of care to use digital technologies for social participation?**	facilitate care recipients using social technology. • Data analysis: descriptive statistics using relative frequencies, mean values and chi-square independent tests. Inductive thematic analysis of fee-text responses.	• Requirements to promote social participation using technology were identified at the micro-, meso- and macro level.	• Future research looking to implement technology in formal caregiving settings such as the nursing homes reported on in *Paper II* may use the identified requirements to facilitate successful uptake, ultimately benefitting dyadic relationships by facilitating social participation by technological means.
Social Isolation during the COVID-19 pandemic and the use of technology among community-dwelling dementia caregiving dyads			
How have COVID-19 restrictions impacted social and leisure activities for community-dwelling dementia caregiving dyads? **How has social technology contributed to mitigating the impact of social**	• Pilot case study based on baseline interview data from the I-CARE study. • Data collection: Participant characteristics and semi-structured interviews. • Interview Topics guide: experiences of the pandemic, living with dementia, social participation, use of technology, technology	• Three community-dwelling dementia caregiving dyads were interviewed, each dyad consisting of a husband with dementia and his wife, performing most caregiving tasks. • Two overarching themes and seven subthemes were identified, including: 1) living with dementia during COVID-19 (subthemes: i) social and leisure activities; ii) dyadic interactions; iii) adjusting as a caregiver); 2) the role of technology in a pandemic (subthemes: i) facilitating social activities; ii) facilitating dementia care-related activities; iii) barriers and facilitators to using social technology; iv)	• Both *Paper III* and *IV* look into the contextual factors influencing caregiving dyads during a time of extreme social isolation. Contrary to *Paper II,* this individual work investigates informal caregiving relationships in the community, and the findings may also here contribute to outlining antecedent factors influencing enrichment processes, such as the caregiving situation. • Although not all participants in *Paper IV* are represented in *Paper III,* the pilot case study reported in this individual work represents the most common typology of dementia caregiving dyads (spousal relationship, with the wife as caregiver),

isolation and limited support offers available to caregiving dyads? **What barriers and facilitators exist in using social technology among caregiving dyads in the context of living with dementia?**	requirements and motivations. • Data analysis: inductive thematic analysis approach. Independently coded by two researchers, with identified themes discussed and refined until achieved consensus.	the underlying motivation to invite technology into interactions. • The interviewed dyads differed in how COVID-19 restrictions impacted them and how they coped with dementia. All three dyads had different motivations for wanting to invite technology into their social interactions. • Social technology has potential to promote social participation for community-dwelling dementia caregiving dyads within and outside a pandemic context.	while simultaneously telling three very different stories in terms of how dementia may impact relationships, how this population utilises social technology, as well as their motivation for inviting technology into their dyadic interactions. • This individual work also reveals many similarities with the requirements identified in *Paper II* and *IV* to facilitate the uptake of technology in a dementia caregiving context, with 'sufficient support' standing as the clearest example. The requirements identified at the micro level in *Paper II*, are directly comparable to those identified in this individual work: While *Paper II* identified *user capabilities, user willingness* and *family support, Paper III* includes requirements that are mirrored in the barriers and facilitators *tech literacy, user willingness* and *sufficient support.* • The barriers and facilitators seem to share many similarities, independent of whether these requirements are identified from the formal or informal caregiving perspective.

Table 2. Continued.

Sustaining togetherness in dementia caregiving dyads using novel technology			
What effects does I-CARE supported social sessions have on community-dwelling PLWD and their family caregiver? **How feasible is the current system design of I-CARE in terms of usability and which adaptations are recommended for a future effect study?** **What barriers and facilitators exist in implementing I-CARE as pertains to the ability of dementia caregiving dyads**	• Mixed-methods feasibility study of I-CARE, a novel technology aimed to facilitate social interactions and positive experiences in caregiving for community-dwelling caregiving dyads. • Data collection: Quantitative: Participant characteristics; dementia quality of life (DEMQOL/DEMQOL-Proxy); Carer Quality of life (Carer-Qol-7D); Burden Scale for Family Caregiving (BSFC); Quality of Caregiver-Patient Relationship (QCPR). Qualitative: Semi-structured interviews. • Interview Topics guide: usefulness and user-friendliness of I-CARE;	• Eighteen participants (n= 9 PLWD; n = 9 caregivers) were recruited to the I-CARE intervention, with 8/9 dyads having a spousal relationship. • I-CARE may be a feasible tool to facilitate enrichment in caregiving dyads: the system showed positive results in terms of usability, given further technical development and proactive technical support. • Positive trends in outcomes for PLWD were observed: a less steep decline in QoL using I-CARE compared to the follow-up period without the system was seen, as well as positive patterns in relationship quality. • For caregivers, the quantitative component did not show equally positive results: QoL had a steeper decline during the I-CARE period (although non-significant) compared to follow-up. Further research with larger sample size and a control group is needed to assess the effectiveness of I-CARE. • The qualitative component allowed a deeper investigation of the impacts of I-CARE on the participants, with the first of two overarching themes, 'The beneficial	• Interest in technology and tech literacy (which fits with the identified subthemes *user-willingness, and user capabilities/tech literacy* from *Paper II* and *III*) seem to be a major facilitator in users' uptake of social technology. • Furthermore, sufficient support is identified as a critical facilitator. This individual work specifies what type of technical support is needed, namely proactive, continuous support tailored to the needs and preconditions of users over an extended time until they feel confident in using the technology independently. • Although technology does not have a specific role in the model of enrichment, this individual work, together with the body of work encompassed in *Paper I-III*, contributes to outlining mechanisms in which technology-driven interventions contain components which may contribute to the core elements of enrichment. • More importantly, the heavy focus on technology in *Paper I-IV* contributes to identifying contextual factors which may influence the preconditions to (antecedent factors), generation of (core elements), outcomes (consequences) of enrichment.

to use the system independently at home?	experiences of I-CARE supported social sessions; barriers and facilitators in using I-CARE independently. • Data analysis: Quantitative: Descriptive statistics, paired t-test of independence. P-values approached in exploratory manner due to small sample size. Qualitative: inductive thematic analysis approach. Independently coded by two researchers, with identified themes discussed and refined until achieved consensus.	effects on the dyadic relationship' containing four further sub-themes: i) enrichment in social interactions; ii) facilitating communication; iii) providing a shared activity; iv) togetherness in the relationship. • The second identified overarching theme, 'Technology requirements' revealed 'barriers to overcome' and 'facilitators to promote' in order to facilitate the experience of the beneficial effects of social technology in a dementia caregiving context.	This may help researchers, healthcare professionals, management/leadership and policymakers to adjust the implementation of social technology in dementia caregiving in order to optimize the chances of successful uptake and ultimately beneficial outcomes that may follow.
Psychosocial interventions promoting enrichment in dementia caregiving dyads			
What psychosocial interventions show potential to generate enrichment among caregiving	• Scoping review. • Primary research (quantitative, qualitative or mixed-methods) describing an intervention, published in English. Reviews	• 34 studies included for review, mainly directed at supporting dyads to engage in shared activities (n=22) or described interventions revolving around carer training and/or education (n=10) • Intervention components contributing to one of the three core elements of	• The results show a wide array of intervention components which may contribute to enrichment in dementia caregiving dyads. • The majority of reviewed studies included informal caregiving dyads, but intervention components possibly

dyads in a dementia context? **What intervention components have been designed to enrich relationships between caregiving dyads?**	included for citation tracking. • Databases: MEDLINE via Ovid, CINAHL, AgeLine, Cochrane Library, and PsychINFO via Ovid. • Two reviewers screening independently. • Critical appraisal: Non-applicable.	enrichment: 'Acquired symbolic meaning': i) core focus on dyadic relationships; ii) supporting communication; iii) common platform for activity engagement; iv) socially oriented caregiving. 'Performing activity': i) dementia-friendly activities; ii) enhancing dementia caregiving; iii) formal carer education and training; iv) informal carer education and training. 'Fine tuning': i) developing and/or specifying goals; ii) emotional support; iii) adapting the environment. • Enrichment in formal dyads requires dedicated space to allow relationships to build and grow, while enrichment in informal dyadic relationships requires consideration of the dyad members' shared history to cope and manage. • Communication support and skill acquisition lay the groundwork to generate enrichment in both formal and informal dyadic relationships	enriching formal caregiving relationships were also identified. • In *Paper V*, eleven intervention components which may contribute to enrichment were identified, which can inform future relationship-centred interventions focusing on both dyad members, for example using technology such as those reported in *Paper I-IV.* • The scoping review only focused on the core elements of enrichment, while antecedent factors and outcomes of enrichment (outlined in Section 2.5) were outside the scope of the individual work. However, the participant characteristics outlined in *Paper III,* and the outcomes identified in *Paper I* and *Paper IV* may contribute further to developing the enrichment model to encompass antecedent and outcome factors when planning and developing relationship-centred interventions in a dementia-caregiving context.

Chapter Six. Discussion

6.1. Identified key issues

The research encompassed in this dissertation explored the potential of technology to support dyadic relationships and social participation in dementia caregiving. The overarching research question comprised five main objectives, each addressed in a separate published article. The findings of each paper summarised above highlight several subjects of further investigation in research, practice and policy. However, the discussion provided in this chapter will condense the five papers into three main areas, as I consider these to be key issues identified from this body of work presented in this cumulative dissertation. These key issues will be outlined and discussed in relation to the wider literature regarding the use of technology to support the relationship between caregivers and people living with dementia. Finally, this chapter is concluded with a discussion of the strengths and limitation of this cumulative dissertation.

The three key issues identified from the summary provided in Chapter Five include:

1. Few studies place focus on the relational dynamics between caregiver and care recipient in dementia caregiving, and how their relationship might be supported.

2. Dementia research evaluating technology-driven interventions supporting social health is still in its infancy.

3. Considerable barriers must be overcome to facilitate the implementation and uptake of social technology in dementia caregiving. COVID-19 has highlighted this need.

6.2. Few studies place focus on the relational dynamics between caregiver and care recipient in dementia caregiving, and how their relationship might be supported

This cumulative dissertation points to a knowledge gap in terms of a lack of focus directed at the relational dynamics between caregivers and care recipients with dementia. As outlined in Section 2.3, relationship-centred approaches are gaining increasing recognition as complementary to person-centredness by including the relationship dynamic between the dyad members [96, 97]. However, the relationship between caregivers and care recipients in dementia caregiving still seems to be the overlooked variable in dementia research focusing on psychosocial factors: Few of the included studies included in the reviews reported on in *Paper I* and *Paper V* aimed specifically to support the dyadic relationship. In *Paper V,* only nine of the 34 studies included for review described interventions with a core focus on supporting the dyadic relationship, while in *Paper I,* relationship aspects as an outcome were only included in four of the 18 reported interventions. As pointed out by Wiegelmann et al.

[82], further research on (informal) dementia caregiving dyads should add relational indicators, "such as relationship quality, relationship closeness or positive and negative dyadic interactions" [82] (p. 14). Their argument was that these indicators are relevant for coping behaviours that in turn moderate health-related outcomes – an argument that is consistent with what is outlined in this cumulative dissertation: relationship sustenance in dementia caregiving, supported by aspects such as positive social interactions and dyadic communication, is highly relevant to how dyads members cope and adjust to dementia, as well as how the disease impacts them. Technology is a potential source of dyadic support that must not be overlooked, and dementia research on social technology must therefore take on a relationship-centred approach.

Closely related to this is the fact that intervention studies in dementia research often do not differentiate between the different typologies of dyads, such as spousal relationships or child-parent relationships. Few of the included studies in the systematic review and the scoping review reported in *Paper I* and *Paper V,* respectively, focused on one specific dyadic type. Some focused specifically on spousal relationships ([175, 176] in *Paper I* and [177-179] in *Paper V*), while the rest categorised different unpaid caregivers (e.g., family members) collectively as 'informal caregivers'. This was also the case for the empirical study reported in *Paper IV,* which due to the objectives of the feasibility trial did not exclude any form of dyadic relationships. This might have implications for the manifestations of outcomes, as research suggests that informal dyadic caregiving relationships are heterogeneous and differ with respect to socio-demographic, relational and regional aspects [82], which may cause significant differences in relevant clinical outcomes for both dyad members [180-183]. However, none of the studies reviewed in *Paper I* or in *Paper V* differentiated between subgroups of dyads beyond formal and informal relationships. *Paper I* found that the studies included for review generally had small sample sizes, something which might limit the opportunities to stratify results according to types of dyadic relationships. This was also the case in *Paper IV,* which had a sample consisting of mostly spousal relationship constellations, but also one dyad of sisters.

Wiegelmann and colleagues found in their latent class analysis that there are typical structural features in dyadic relationship constellations, allowing for the identification of typical dyadic subgroups [82]. Six different classes of dementia caregiving dyads were identified, where the key characteristics distinguishing the classes were related to the relationship type and the age of the informal caregivers. Their findings suggest that the differences among care dyads must be carefully reviewed in the design and implementation of interventions in dementia caregiving, such as counselling, service use and ease of caregiver burden. Psychosocial interventions to support relationship sustenance should therefore also adjust according to the dyadic constellations, as enrichment in caregiving might manifest differently in spousal relationships compared to child-parent caregiving relationships.

Although Wiegelmann and colleagues' argument revolves around informal dyads, attention should also be directed at formal caregiving relationships. Caregiving staff's relationship with their care recipients has been recognised as central to their sense of purpose, achievement and significance [8]. However, proper structures need to be in place to facilitate the flourishing of such relationships. As advocated by Stone in 2001: "The relational aspect of care must be rewarded, both monetarily and spiritually, so that workers continue to be motivated to engage in the most important of non-instrumental tasks of caring" [184] (p. 173). Although this statement was made more than two decades ago, it harmonises with the findings of *Paper V,* which argued that dedicated resources are needed in formal caregiving to support positive social interactions and build dyadic relationships. However, to the best of my knowledge, there are few studies looking at the relational dynamics between staff providing care and their care recipients with dementia. As mentioned above, nine of the reviewed studies in *Paper V* had a core focus on dyadic relationships. Of these nine, only one focused on dyad members in formal caregiving relationships [185]. In *Paper I, none* of the four reported studies that included relationship aspects as an outcome focused on the formal caregiving relationship. However, outcomes that may indirectly influence the formal dyadic relationship were reported, such as increased social interactions, facilitated communication and a point of joint attention. As such, there seems to be room for assessments of relationship quality in formal caregiving dyads and how this aspect might influence outcomes for both dyad members. Directed attention to the caregiving relationship might even provide further rationale for establishing technology-driven strategies to facilitate positive social interactions between formal caregivers and PLWD in settings like nursing homes.

Although *Paper II* describes the results of cross-sectional data collected from German nursing homes, the relational aspects between nursing staff and residents with dementia were outside the scope of the study. The findings nevertheless have important implications for future technology-driven interventions in dementia caregiving: the high frequency of respondents reporting support provided to residents with dementia to use social technology (despite having no established procedures in doing so), might indicate a significant willingness among formal caregivers to use technology in social interactions with PLWD. As found in *Paper I,* technology-supported social interactions might lead to beneficial outcomes for both care recipients and their formal caregivers. The focus, however, should not only be on outcomes related to the individual dyad members but also on whether technology-supported social interactions might positively influence the caregiving relationship. As outlined in Chapter Two, engagement in social activities (technology-driven or otherwise) perceived as meaningful can increase staff satisfaction, which may again feed back into the relationship. Taking on a relationship-centred approach when implementing and assessing technological solutions in formal caregiving contexts could also lead to discoveries in formal caregiver outcomes such as job satisfaction, sense of competence, burnout and staff turnover.

6.3. Dementia research evaluating technology-driven interventions supporting social health is still in its infancy

Further research is required to ensure that social technology in psychosocial interventions is as effective as possible, increasing the chances of these interventions being translated into standard care practices and covered by statutory healthcare schemes. However, there is a dearth of high-quality studies researching social health in dementia. The establishment of effectiveness requires methodologically rigorous studies with strong statistical power, including larger sample sizes with control conditions, and longer follow-up periods to assess the sustainability of effects [57, 58, 186-188]. As found in *Paper I,* the quantitative components in the reviewed studies on technology-driven solutions to support dyadic social interactions were mostly of low methodological quality. In addition to the sample sizes (mentioned in Section 6.2), few studies included control groups and even fewer had follow-up measures. This is not the case only in technology-driven interventions supporting dyadic social interactions in dementia caregiving: Similar reviews on technological solutions in socially oriented dementia caregiving find few studies with high methodological quality [57, 58, 186-188]. The I-CARE intervention reported on in *Paper IV* adds to the body of research literature with limited generalisability. The small sample size and lack of a control condition allowed only an exploratory approach to marginal significance levels. This was mainly due to limitations imposed by the COVID-19 pandemic, with posed a major barrier to the recruitment of participants. Additionally, the results were limited by the short duration of both the intervention- and follow-up periods. The effectiveness of this tablet-based activation system must be established through large-scale randomised controlled trials (RCTs) with longer durations of observation, comparing I-CARE to existing tablet-based interventions for the provision of social health for PLWD and their caregivers.

Although it is important to demonstrate the effectiveness of social technology in promoting social health and relationship sustenance among dementia caregiving dyads, strong statistical power cannot be sought at all costs. RCTs are by many researchers considered the gold standard for studying causal relationships, superior to all other types of evidence [189]. However, recent years have seen increased calls for studies that go beyond the traditional RCT design to enable a broader examination of effectiveness in a real-world context [189, 190]. Furthermore, RCTs have been criticised for being rigid and suboptimal in certain circumstances. For instance, in psychosocial interventions advocating for relationship-centred (or even person-centred) approaches, an RCT might not always be the most appropriate study design. Moreover, in a population living with dementia, behavioural and psychological changes following an intervention are not always reflected in an RCTs chosen assessment scales [190]. Grossman and Mackenzie argued that in psychosocial interventions, an RCT study design only makes sense if the randomisation and analysis are done at the societal groups level rather than at the individual level [189], which might be counterproductive when assessing relationship dynamics; some instruments might not be sufficiently sensitive to capture changes in outcomes that might be of interest, especially if these are too intangible to measure using standardised measurement instruments. This necessitates a means to look beyond these outcome measures for an overall evaluation of intervention effectiveness.

Qualitative research can offer invaluable insights beyond standardised outcome measures when evaluating psychosocial interventions. Quantitative research is undoubtfully essential to drive dementia research within social health forward, however, despite qualitative research being limited in terms of generalisability and context-dependency, the value of such research should not be trivialised. As found in the systematic review reported on in *Paper I,* qualitative research methods were able to provide insights into outcomes where quantitative, standardised outcome instruments fell short. The argument provided in *Paper I* was that although rigorous investigation using comparable instruments is needed to establish the effectiveness of technology in psychosocial interventions, qualitative studies play a crucial role in providing a deeper understanding of quantitative results. The qualitative component in *Paper II* also provided more insight as to why there were so few respondents reporting on established procedures in using technology together with care recipients with dementia. By including a qualitative component, important requirements at the micro-, meso- and macro-level could be identified, which may inform future interventions in nursing homes aiming to implement or facilitate the uptake of technology as a strategy to promote social participation among residents with dementia. Information gathered from interviews reported in the systematic literature review in *Paper I,* in the free-text comments gathered in *Paper II,* and as well as with the semi-structured dyadic interviews reported in *Paper IV,* offered a vital supplement to the quantitative outcome measures. Especially in *Paper IV,* the qualitative component allowed a more comprehensive picture of how novel technology like I-CARE could contribute to relationship sustenance among dementia caregiving dyads, in a way that would not have been possible to capture with purely quantitative outcome measures, regardless of how big the sample size. The qualitative components in this body of work provided crucial insight into the carers' and care recipients' experiences, enabling the research to go beyond the measurement of outcomes and tap into factors that are of great importance to these individuals. Mixed-methods or multi-methods approaches should be employed when assessing technology-driven interventions for caregiving dyads in a dementia context.

Nevertheless, the quantitative component of such hybrid research designs must be carefully considered and closely linked to the aims of interventions using outcome measures. As argued in *Paper I,* the lack of standardised measurement instruments aiming specifically at measuring the relational dynamics in caregiving dyads, such as communication and positive social interactions, point to a knowledge gap in dementia research. Greater attention directed at quantifiable outcome measures in dyadic relationships is required; as outlined in the body of work in this cumulative dissertation, they are pivotal in maintaining and enhancing relationships. Here, however, there seems to be a significant scope to improve the consistent and appropriate use of these measures in dementia research. One major issue with quantitative research assessing psychosocial interventions in dementia is the large volume and heterogeneity of measured outcomes and instruments measuring these [57, 191-

193]. This is consistent with the findings in *Paper I,* which problematised the wide range of methodologies and outcome instruments in the studies included for review. This finding is supported by Couch and colleagues, who found in their recent scoping review of outcome measures in non-pharmaceutical interventions for PLWD that only 22 % of their 358 extracted individual outcome measures were used in more than one of the included studies [194]. Couch et al. also found that cognition was prioritised over other domains despite existing evidence emphasising the importance of quality of life and outcomes for caregivers of PLWD. Even within quality of life outcomes measures, many of the key outcome instruments used in dementia research have been found to lack a theoretical basis and insufficiently include the views of stakeholders with lived experience, especially PLWD themselves [195].

This brings us to another central issue in quantitative research of psychosocial and non-pharmaceutical interventions in dementia: the relevance of this vast array of measurement instruments. Tochel and colleagues found in their systematic literature review of outcomes important to PLWD and their (in)formal caregivers, that intervention studies rarely include outcomes that are considered important to non-professional stakeholders [196]. Research may aim to produce high-quality evidence that will improve the lives of PLWD, but if outcomes and measurement tools are not relevant to all stakeholders, especially those who live with or care for someone with dementia, it raises the question of whether this objective is aimed correctly. Further investigation is needed to highlight which outcome measures should be prioritised in dementia research [194]. As a way of addressing these challenges of relevance and heterogeneity in outcomes and measurement instruments, recent years have seen increased calls for the development of core outcome sets (COS) [191, 194]. If the concept of enrichment in dementia caregiving is to be built upon and extended, it would be valuable to develop a core outcome set on enrichment in dementia caregiving. The implications of this are discussed in Section 7.2.3.

6.4. Considerable barriers must be overcome to facilitate the implementation and uptake of social technology in dementia caregiving

Technology-driven solutions to facilitate social health in dementia is a growing area of carer support, and may help enable PLWD to function according to their competencies and capacity – a central goal in social health interventions [31, 57, 197]. The SARS-CoV-19 pandemic has exposed the urgency of the need for effective technological solutions for social interaction [30, 57, 198]. This is the case for both formal and informal caregiving constellations, as social interactions were severely limited in both the community ([150, 151, 199] and as reported in *Paper III* and *IV*) and institutional settings ([137, 200, 201] and as reported in *Paper II*). In light of the pandemic-induced social isolation, and the existing evidence on the importance of social health for PLWD and their caregivers (as outlined in Chapter Two), this cumulative dissertation suggests that there is an unexploited potential for social technology in dementia caregiving. However, the successful implementation and use of technology in dementia caregiving depend not only on its efficacy, but also on other barriers and facilitators on a micro, meso and macro level [133]. Specific requirements related to these three levels were identified in *Paper II.* Many of the barriers and facilitators identified at the micro-level in *Paper II* were also found in *Paper III* and *Paper IV*, such as user capabilities, user willingness and available support.

6.4.1 Barriers at the micro-level

An important barrier related to user capabilities, as identified in *Paper II-IV,* is the limited tech literacy among older adults. Despite the rapid pace of technological innovations, many older adults living with dementia and their formal and informal caregivers are not existing users of technology, showing a clear age-related divide [202]. However, this will change in the time ahead: The potential for social technology in facilitating positive social interactions and supporting caregiving relationships continues to grow as new cohorts of people, familiar with technology, receive a diagnosis of dementia [202]. Considering gloomy predictions of the prevalence of PLWD estimated to triple by 2050 [3-5], and the associated cost with dementia care provision [4], it seems beneficial for caregivers and services (in terms of optimising existing caregiving structures as well as potential cost saving implications) for social technology to be developed so that more individuals may benefit. As familiar (such as personal computers, tablets and smartphones) and novel (such as smart home solutions, social robots and VR technology) social technology becomes increasingly ubiquitous in everyday life, the viability of social technology interventions increases along with decreased costs for service providers with the growing number of individuals owning requisite technology in their homes.

This does not, however, diminish the need to create user-friendly technology specifically adapted for a dementia context. User-friendliness was identified in *Paper II* as an important technology-related requirement, which was also central in the assessment of I-CARE's usability in *Paper IV*. It seems like user-friendliness may be interpreted as a supplier-side requirement mirroring the micro-level requirements such as user-willingness and tech literacy. User-friendliness, as outlined in *Paper IV,* refers to whether users believe an application will be easy and simple to use [167], a definition which shows the clear connection to the identified micro-level requirements of user willingness and tech literacy. It is well-established that ease of use is dependent on the content of use, in addition to the goals and characteristics of the user [203, 204]. If social technology is to be appropriate for older adults, with or without dementia, it must be designed with the end-users in mind. Examples of such considerations provided by respondents in *Paper II* included large displays, few buttons, and a voice assistant function. As found in *Paper III,* user-willingness is not merely dependent on the individual's aversion or openness to trying novel technology, but also on having sufficient support in doing so. User-friendly technology can be considered a central aspect of such support.

In order to meet the needs of the target population, researchers increasingly utilise a user-centred design to refine devices and technology [65, 205-208]. As outlined in *Paper IV,* the I-CARE system was developed while actively involving participants in the design and selection of activation content. Nevertheless, usability issues related to user-friendliness were found together with the occurrence of technical errors. Although the system was overall considered to be user-friendly, some of the participants got lost while navigating the system, and the activities' difficulty levels were too complex for some participants with more advanced stages of dementia. These considerations should be addressed before moving forward with assessing the effectiveness of I-CARE in large-scale trials. I-CARE shows potential in being a valuable social technology resource to promote social health and dyadic relationships in dementia. The usability issues identified in *Paper IV* show the importance of feasibility trials even with smaller sample sizes, as these give room to address crucial improvement points before scaling up the intervention [44, 209, 210].

6.4.2 Barriers at the meso-level

Moving from barriers and facilitators at the micro-level to the meso-level, *Paper II* identified three important requirements to support the implementation of social technology: i) technical support; ii) training; and iii) sufficient resources. Although technical support was identified at the meso-level, this requirement echoes similar micro-level facilitators found in *Paper III* and *IV*, revolving around having sufficient support available when facing novel technology. Similar to the needs of the informal dyad members in *Paper III* and *IV*, caregivers in formal dyadic relationships need support to avoid being overwhelmed and discouraged from engaging with the technology. Such support was in *Paper II* emphasised as necessary not only during the implementation, but continuously. Such continuity of support was also highlighted in *Paper IV,* which found that continuous and proactive support for end-users when using novel technology to ensure the successful uptake of social technology such as I-CARE. Although the setting and thereby the needs and prerequisites of the caregivers in nursing homes (*Paper II*) are different from caregivers in the community (*Paper III* and *IV*), there seems to be a substantial overlap of requirements across settings and analytical levels in terms of successfully employing social technology in dementia care. *Paper II* also highlighted that technical support should be provided by dedicated personnel in a supportive role, rather than being the responsibility of the care providers. The requirement of sufficient support is therefore also closely connected to the identified need for sufficient resources. In *Paper II,* this requirement at the meso-level was accentuated as time and personnel. Lack of time and manpower is a well-known barrier to implementing social technology in care facilities [59, 211, 212]. Protected time and dedicated space therefore seem vital to enable social technology to support positive social interactions in formal caregiving dyads. Similar implications were made in *Paper V*, despite the scoping review not focusing exclusively on technology-driven psychosocial interventions: Space seemed crucial in order to facilitate positive social interactions (technology-supported or otherwise) in formal caregiving contexts, where room for social interactions beyond basic care may be quite limited. Dedicated resources such as protected time were suggested to enable dyadic relationships to build and grow.

The third requirement identified at the meso-level in *Paper II* was related to the training of staff in the nursing home. This is again similar to findings in *Paper V,* where training or education of formal caregivers were also identified as important categories of psychosocial interventions contributing to enrichment in caregiving relationships. Training or education modules included (but were not limited to) providing optimised care through improved interactions [213-215] and engaging PLWD in social activities using supportive tools [185, 216], either with or without the use of technology. Training and education may therefore be considered as imperative in equipping caregivers with necessary skills to use social technology with PLWD in their care. However, returning to *Paper II,* the findings showed that the vast majority of caregivers in German nursing homes had received no training whatsoever in using technology to promote social participation among their care recipients. Of those who had received *some* training, 32 % had less than two hours, while 6 % received at most half-day training. There seems to be a lack of governmental regulation or educational provision guiding how current and future technology may be implemented and used to promote social participation in dementia caregiving. Furthermore, the results from *Paper II* indicated a low use of technological solutions such as those identified in *Paper I* as most commonly used to facilitate communication and social interactions in caregiving dyads (e.g., social robots and mobile applications). Since these types of social technology were most commonly found to facilitate positive social interactions and dyadic communication, dedicated efforts should be directed at providing necessary training and education on how to implement and operate social technologies such as tablet computers and social robots in nursing homes. Equipping formal caregivers with the necessary knowledge and skills with novel social technology seems essential if social technology is to be established as a standard offer in formal caregiving. Such training and education should be informed by operationalised guidelines for design and implementation must be developed, underpinned by the principles of relationship-centred care. The implications of this requirement are elaborated in detail in Chapter Seven.

6.4.3. Barriers at the macro-level

The final, yet overarching requirements to enable to successful implementation and uptake of social technology in dementia caregiving are identified at the macro-levels. Outlined in *Paper II* these included network infrastructure and cost coverage. Shortcomings related to network infrastructure is a well-known and long-debated issue in Germany [217], where all empirical studies encompassed in this dissertation were conducted. In *Paper II,* respondents expressed their frustration over the poor internet broadband coverage, which they perceived as a barrier to the practical use of technology among caregivers and care recipients. This barrier is also highly relevant for community-dwelling dementia caregiving dyads. Although this requirement was not explicitly stated in *Paper IV,* not all participants had internet access, and therefore needed to have their I-CARE tablets equipped with a sim card in order for them to participate in the intervention. Proper network infrastructure is therefore a permeating requirement in order to further the uptake of social technology in dementia caregiving, as we become increasingly dependent on internet availability. On the one hand, the Internet is essential in connecting users remotely, while on the other hand, the digitalisation of the domestic and residential caregiving environments is accelerated by the Internet of Things technology [36, 218, 219].

Cost coverage was identified as the second overarching requirement outlined in *Paper II,* as an important requirement for dementia care policy. There was a consensus that neither care recipients nor service providers should incur the costs of acquiring social technology, as this may deter the uptake and implementation of social technology as a standard offer in institutional care. Cost coverage seems especially important for community-dwelling caregiving dyads, as the costs of social technology may limit the accessibility for certain socioeconomic classes [4]. Although the cost of technology like I-CARE was not voiced as a concern by the participants in *Paper III* and *IV,* societal efforts in promoting the uptake of social technology should be coordinated with health policy plans that can mitigate unintended societal consequences, such as the digital divide between PLWD and caregivers who can afford social technologies and those who cannot [173]. As access and affordability are critical predictors of technology adoption [173, 220, 221], social technology should be included in healthcare insurance schemes on an equal basis to assistive technology. With hardware, software and internet broadband covered for end users, the accessibility of social technology can be ensured on an equity basis, safeguarding the social health of PLWD across all socioeconomic classes.

Overall, this thesis advocates for using social technology to support social health, facilitate experiences of enrichment and sustain relationships. The systematic literature review (*Paper I*) and the empirical study of I-CARE (*Paper IV*) found no evidence of adverse outcomes using technology to facilitate social interaction and communication. These promising findings may contribute to advocating for efforts to be dedicated to addressing the barriers outlined above. This, in turn, may pave the way to slowly increasing the accessibility and availability of social technology as a means to support the social health and relationship sustenance of PLWD and their caregivers. However, as technology is developed to provide increasingly sophisticated systems addressing psychosocial needs [131, 218, 222], there is growing concern about issues related to data protection, privacy and misuse of data [173, 223-225]. Due to technology's omnipresent nature, it does not only influence the clinical dimensions of PLWD (as outlined in Chapter One), but their emotional, psychosocial and relational dimensions as well [173]. The types of social technology encompassed in this body of work function as prime examples of this influence. Therefore, if social technology is to be implemented in a safe manner, there is an overarching need for robust and effective legislation to safeguard the privacy, data agency and safety of end-users. Legal frameworks for social technology were the focus point of the identified technology requirements in *Paper II,* however, the role of policymakers to safeguard end-users of such technology must not be trivialised; developers and providers of technology cannot let monetary interests be prioritised at the expense of the safety and well-being of end-users, both PLWD and their formal and informal caregivers. Furthermore, as discussed above, there is an age-related divide in tech literacy [202], which might limit the competencies of older adults providing care for PLWD to provide informed consent to the data collected and used through their engagement with technology [208, 226]. Moreover, ageing often involves changes in decision-making practices [227]. End-users' limited legal competence or declining decision-making capacity impacts the ethical and legal responsibilities and duties of technology suppliers, policymakers and regulators [228]. Therefore, in addition to the macro-level requirements identified in *Paper II,* legislation is needed to ensure the empowerment of individuals to specify their agency, including accessing and controlling their own personal data [229, 230].

6.5. Thesis strengths

The body of work comprising this dissertation has identified influencing factors on the usage of social technology and its effects on social health aspects of PLWD, their (in)formal caregivers and their caregiving relationship. The thesis is underpinned by recognised concepts of social health and enrichment in caregiving. By building and extending the theoretical model of enrichment, the overarching theme of relationship sustenance through social participation and positive dyadic interactions in dementia caregiving could be rigorously explored. This exploration was underpinned by a scoping review charting the evidence of psychosocial intervention components that may contribute to enrichment in such relationships, regardless of whether technology is involved or not. In addition, the thesis was informed by a systematic literature review involving 18 studies that outlined technology-driven interventions for PLWD and their caregivers to prompt communication and facilitate positive social interactions. The research reported in the five peer-reviewed papers records that a comprehensive exploration of how social technology is and can be utilised in caregiving relationships has been conducted. Relevant research literature was comprehensively reviewed using robust methodologies and the findings of the literature review informed the content and analysis of the empirical research, supported by the scoping review.

The empirical studies examining the usage of social technologies in both formal and informal caregiving relationships were designed and conducted using rigorous methodology. The studies reported in *Paper II* and *IV* employed mixed-methods approaches to investigate complex issues. Utilising mixed-methods approaches enabled a widened inquiry with sufficient breadth and depth in a way that a single-method approach cannot provide using only quantitative or qualitative methods [231]. By mixing quantitative and qualitative data, a more complete picture of the underlying factors influencing the actual (or the hindrance of) use of social technology could be attained, providing an opportunity for a greater assortment of both complementary (as in *Paper II*) or divergent (as in *Paper IV*) views. The way in which I-CARE seemed to generate positive outcomes, as observed in the quantitative findings (*Paper IV*) could be understood in more comprehensive manner by the qualitative component. The sample characteristics in *Paper II* and *Paper IV* limited the extent to which statistical inferences could be made. Nevertheless, the study participants' experiences and opinions provided a deeper insight into complex issues in the qualitative component of the studies, which was analysed using rigours qualitative methods. The qualitative data in *Paper II-IV* were all subjected to inductive thematic analyses following a well-known and internationally recognised analysis framework developed by Braun and Clarke in 2006 [160], which since then (according to Google Scholar) has been cited more than 140 000 times across multiple disciplines and research areas.

6.6. Thesis limitations

There are limitations to the body of work presented in this thesis, and the limitations have been discussed within each paper encompassed in this thesis. Overall, this doctoral thesis is based on a relatively limited body of existing literature. This is mostly due to the novelty of technologies used in psychosocial interventions aiming to support social participation and relationship sustenance in dementia caregiving dyads. These limitations are already discussed in Section 6.3.

Another limitation lies with the theoretical concept of enrichment underpinning this thesis. As outlined in Section 2.5, enrichment, according to Cartwright and colleagues, encompass more than just the three core elements outlined in *Paper V.* Enrichment also includes antecedent factors (i.e., the individual characteristics of the dyad members and their relationship) and consequences of enrichment (i.e., outcomes for the caregiver, the care recipient and the dyad as a unit. The influencing (antecedent) factors and the realised individual or relational outcomes (enrichment consequences) following psychosocial interventions containing enriching components fell outside the scope of *Paper V*. These factors are undeniably important to fully understand how enrichment might support relationship sustenance in dementia caregiving, and what psychosocial interventions (technology-driven or otherwise) may contribute to such support. However, with no existing framework for systematically promoting enrichment in the context of dementia, this cumulative dissertation may be considered the first brick in an extensive groundwork focusing on the positive aspects of dementia caregiving.

The following limitations relate to the empirical studies encompassed in this oeuvre. First of all, the studies related to I-CARE (*Paper III* and *Paper IV*) included small sample sizes. Although the feasibility of implementing I-CARE was investigated, the small sample size limits the generalizability of the results. However, the unprecedented circumstances of conducting empirical research during a global pandemic – despite severely limiting the recruitment efforts of participants – have also offered unique opportunities to investigate the impacts on social health aspects such as social participation and relationships in a time where the norm was to avoid anything social for the sake of preventing infection.

The findings from the empirical study of the social health in German nursing home residents with dementia (*Paper II*) must also be interpreted with caution, as the reported observations were collected at the managerial level and might differ from healthcare professionals providing direct care to their residents with dementia. This is also the main reason for the focus of *Paper II* not including relationship aspects between caregiver and care recipient, but rather focused on the social participation of PLWD supported by caregivers using social technology.

Another important limitation in the empirical studies encompassed in this cumulative dissertation is the limited inclusion of perspectives from PLWD. The reviews of existing literature in *Paper I* and *V* advocate for increased dyadic focus in dementia research, with *Paper V* explicitly calling for increased relationship-centred approaches in dementia research and clinical care. The empirical studies reported on in *Paper II-IV* can be interpreted as important attempts to exhibit the perspectives of PLWD. However, in the qualitative components of *Paper III* and *IV,* the contributions from the dyad members with dementia were quite limited. This was mostly due to the advanced stage of dementia in some of the participants and thus, the carers' experiences dominated the interviews. In *Paper II,* none of the residents with dementia in the included nursing homes were surveyed, as the cross-sectional study was nested within a larger national online survey that was intended for healthcare providers rather than care recipients. Hence, it was impossible to include the experiences and perceptions of nursing home residents with dementia regarding the impacts of the COVID-19 pandemic on their clinical and social well-being. These perspectives were obtained from the managerial level of the participating nursing homes. As a result, dyadic information cannot sufficiently be achieved from these studies. Although the empirical studies encompassed in *Paper III* and *IV* demonstrated the opportunity to directly include PLWD in research, the dyadic perspective is not fully considered, meaning that further investigation is needed to achieve a comprehensive understanding of the impacts of social technology on dyadic relationships.

Chapter Seven. Implications for future research, practice and policy

7.1. Chapter introduction

This chapter section discusses implications for future research, practice and dementia care policy. Section 7.2 addresses areas of research deserving of increased attention and resources in the efforts of reducing the knowledge gaps described in Chapter Six. Section 7.3 outlines some implications of how relationship-centred care and implementation and uptake of technology-driven solutions in clinical practice may further enhance dementia caregiving in a way that is beneficial for PLWD, their caregivers, and a more socially oriented utilisation of healthcare services in general. Section 7.4 addresses the implications for dementia care policy in terms of what is needed to safeguard the social health of PLWD and their caregivers, not only today, but in the years to come as we strive to live as well as possible with dementia, with the gloomy predictions of a worldwide tripling of dementia cases by 2050.

7.2. Implications for future research

The body of work comprising this cumulative dissertation has illustrated the importance of relationship-centred research taking on a positive discourse to dementia caregiving. This positive discourse is encompassed in the concept of social health, which provides an overarching lens through which our endeavours to better the health and quality of life of PLWD can be brought into focus [33]. As outlined in Chapter Two, and echoed in *Paper I-V*, the concept of social health plays a key role in shifting the traditionally reductionistic understanding of dementia towards focusing on remaining strengths and capabilities. Social health should thus be included in models of both causes of dementia as well as models to reduce its consequences [33], such as technology-driven solutions.

7.2.1. Future employment and validation of the enrichment model

Within the sphere where social health and technology meet in dementia research, the theoretical model of enrichment shows potential in providing a useful framework when developing, implementing and evaluating psychosocial interventions taking on a relationship-centred approach. The psychosocial intervention components identified as possibly contributing to enrichment are consistent with the enrichment core elements proposed by Cartwright and colleagues back in 1994, which guided the work of *Paper V* and provided valuable insights into the potential of technology in supporting dyadic relationships, beyond just reported intervention outcomes. The identified research literature in *Paper V* was in line with the enrichment model, a promising indication of the potential of validating the theoretical assumptions postulated by Cartwright et al.

As described in Chapter Two, the model of enrichment has not previously been utilised in dementia caregiving research. Future research should therefore investigate whether the development, investigation and future deployment of social technology can be theoretically underpinned by the theory of enrichment. This thesis has directed focus at the core elements of the enrichment model, while the antecedent (contextual factors) and consequences (outcomes) of enrichment have not yet been under rigorous scrutiny. Further investigation should be directed at operationalising and contextualising these aspects of the enrichment model. Antecedent factors, which in the enrichment model includes aspects such as 'the caregiving situation', may be informed by the identified overarching theme in *Paper III* (i.e., 'living with dementia during COVID-19'). The outcomes identified in *Paper I* and *Paper IV* may also value-add the operationalisation and contextualisation of enrichment consequences. By continuing the work reported in *Paper V*, informed by the body of work in this thesis, the enrichment model might lead to innovative approaches when working towards enhancing the social health and well-being of the dyad as a unit of attention. With the current shift in focus from disability and limitations towards strengths and remaining capabilities, the enrichment model can provide a valuable contribution towards a positive discourse influencing society's perception of dementia. This may ultimately lead to more resources for developing interventions and tools (digital or otherwise) aiming to facilitate positive experiences in caregiving.

7.2.2. Larger investigations and assessments of social technology in dementia caregiving

The I-CARE system's feasibility has now been evaluated on a small scale, but its efficacy in fostering relationship sustenance and promoting social participation in dementia caregiving dyads as essential components of social health and enrichment, compared to the impacts of a standard touchscreen tablet has not yet been investigated. As mentioned in Section 6.6, strong limitations were imposed on the feasibility trial in *Paper IV*, severely hindering the recruitment efforts and limiting the opportunities to assess I-CARE over longer periods of time. Future trials investigating the impacts of I-CARE should include longer durations of the intervention, as well as longer follow-up periods in order to enable meaningful assessment of the sustainability of effects. In addition, the findings of this thesis need to be verified by conducting large empirical studies with larger sample sizes and control groups. As p-values were approached in an exploratory manner, the positive trends observed in *Paper IV* cannot be firmly established before rigorous investigations including large sample sizes and control conditions have been made. These large-scale trials should, however, not trivialise the importance of a qualitative component. As demonstrated in *Paper II-IV*, qualitative research contributes to enhancing our understanding of contextual influences through the experiences, perceptions and opinions of our target research group. The quantitative outcome measures should be complemented by a qualitative research component. Even with the demonstration of effectiveness of social technology on dementia caregiving dyads, the testimonies from individuals' lived experience may contribute to raising awareness as of the "why" social health and relationship sustenance is important in dementia research and caregiving. This, in turn, may influence public opinion and thereby the willingness of policymakers to dedicate more resources to social technology. Future assessments and investigations of not only I-CARE, but all forms of social technologies for caregiving dyads in a dementia context, would benefit from employing mixed-methods or multi-methods approaches.

However, stakeholders and policymakers might be disinclined to invest in and implement new solutions that cannot be proven effective, less so cost-effective. Cost-effectiveness studies are needed to determine the efficiency of technology-driven interventions (such as I-CARE) once effectiveness has been established. In the case of I-CARE, such efficiency analyses must be carried out to compare the cost-effectiveness of tablet-based interventions such as I-CARE to published analyses of other interventions designed to enhance dyadic relationships and social participation in dementia caregiving. Before such cost-effectiveness analyses can be made, research projects must strive to produce results that are comparable. As discussed in Section 6.3, there is a substantial heterogeneity of measured outcomes and measurement instruments in psychosocial interventions in dementia research [57, 191-193]. The development of Core Outcome Sets (COSs) in psychosocial dementia research is essential in prioritising what should be measured. A COS can reduce the heterogeneity while ensuring that outcomes assessed in dementia research actually are considered important to all stakeholders, including those with lived experience. Developing a COS of enrichment in dementia would add great value to the shift toward a positive discourse influencing public perception of dementia.

7.2.3. The development of a core outcome set on enrichment in dementia caregiving

The development of a core outcome set (COS) on enrichment could be of great value in dementia research in general, as a COS would enable comparison between future relationship-centred interventions aiming to contribute to positive aspects of caregiving. The enrichment consequences postulated by Cartwright et al. [105] provide a good starting point to develop a COS of enrichment, but these should also be operationalised and contextualised to dementia caregiving. This process could draw upon the work of Harding, Reilly and colleagues [191, 232, 233]. They identified 13 outcome items considered core in evaluating non-pharmaceutical interventions for PLWD in their work to establish an agreed standardised COS. Many of these core items were related to social health, such as ‘communication’, ‘meaningful activities’, ‘feeling valued and respected by others’ and ‘having a laugh’. However, the first core outcome identified by the authors explicitly shows the potential value in developing COS within this enrichment: ‘Importance of relationships’, described as “Continuing good relationships with people who are important to you” [232] (p. 668), implies just how relevant enrichment in dyadic relationships truly is.

Using Cartwright and colleagues’ concept of enrichment as a point of departure, informed by the extensive work of Harding et al., the COS of what constitutes enrichment for dementia caregiving dyads could enable spearheaded efforts to be placed in psychosocial interventions, giving adequate attention to relationship-centred approaches. This development work can be further supported by the body of work in this thesis, as well as existing research advocating for using the concept of social health as outcome measures when evaluating psychosocial in the context of dementia [31, 32, 68]. Not only would this facilitate consistent comparisons be made between psychosocial interventions targeting caregiving dyads as a unit of attention – a COS would also address the issue raised by Bowling and colleagues (outlined in Section 6.3) of lacking theoretical basis in key outcome measures [195].

7.3. Implications for future practice

As outlined above in Section 7.2.1, the enrichment model may prove a valuable framework when developing and implementing either psychosocial interventions or digital tools in dementia caregiving. However, there is a well-documented gap between research and practice [234], with many trials of psychosocial interventions in dementia caregiving lacking impact [235]. Vernooij-Dassen and Moniz-Cook argued that given the current budget constraints and the increasing number of PLWD that may benefit from psychosocial interventions, practitioners and service organisations deserve dedicated attention to existing barriers and facilitators in the application of new interventions [235]. The body of work encompassed in this dissertation has outlined several such contextual factors. Despite their promise to positively impact the psychosocial health of older adults and PLWD, the implementation of technology in real practice remains a challenge [15, 235]. Considering the findings from the individual works encompassed in this cumulative dissertation, two main recommendations for practice in dementia caregiving can be derived.

7.3.1. From person-centred to relationship-centred dementia caregiving

This body of research has highlighted the importance of clinical care approaches that go beyond person-centred toward relationship-centred care. This requires recognition of the mutual influence dyad members have on each other, and their relationship as a whole [88]. As outlined in Chapter Two, relationship-centred care is gaining increasing recognition as a supplementary model to person-centred care, with a central argument being that relationship-based approaches are built around that care takes place within the relationship, while the relationship is necessary for person-centred care [88, 236]. Therefore, relationship-centred dementia caregiving must focus on the interactions between caregivers and PLWD [88]. Furthermore, future practice should direct their attention to making these interactions positive and thus shifting the negative discourse that so long has dominated society's perspective on dementia care [32, 69]. The theoretical framework of enrichment in formal and informal caregiving relationships may prove useful in this work, and should guide socially oriented caregiving – both in formal and informal care. Enriching activities in dementia care can provide a vehicle to maintain or strengthen dyadic relationships and enhance positive outcomes for both caregiver and care recipient [129].

Relationship-centred care is especially important if the psychosocial intervention utilises technology to support dyadic interactions. As outlined in this cumulative dissertation, technological solutions might be vital supporters of facilitating and supporting such enriching activities. However, if technology is used to fulfil the needs and preferences of only one dyad member– e.g., in terms of respite for the caregiver providing activities the care recipient can engage with alone – rather than the dyad as a unit, the technology is unlikely to promote enrichment in the dyad. By taking on a relationship-centred approach (rather than purely a person-centred one) when implementing familiar or novel technology in dementia caregiving, the needs, preferences and prerequisites of *all* end-users are sufficiently considered. This may ultimately increase the probability of a successful translation from research into practice [59, 237-239]. Technology designed to be used in a dementia caregiving context should thus be developed using a relationship-centred approach that sufficiently includes both the care recipient, and their formal or informal caregiver.

7.3.2. Established guidelines to incorporate technology as standard supplement to dementia caregiving

As discussed in Chapter Six, there is a lack of governmental regulation or educational provision guiding how current and future technology may be implemented and used to promote social participation in dementia caregiving. However, clinical practice might benefit from using existing guidelines when seeking to implement social technology in formal caregiving. A useful starting point may be the Best Practice Guidance, developed in two Marie Skłodowska-Curie funded Innovative Training Network projects (MSC-ITN), INDUCT (2016-2020) and DISTINCT (2019-2023), the latter of which I am a part of as an Early Stage Researcher (ESR). The Best Practice Guidance results from the literature and field research conducted in both projects, where the main focus areas of INDUCT were everyday life, meaningful activities and healthcare, while DISTINCT focuses on the three social health dimensions outlined in Section 2.2: The overarching objective of DISTINCT is thus to provide the evidence to show how technology can improve the social health of PLWD by enabling them to i) fulfil their potential on a societal level, ii) manage their own life and iii) participate in social and meaningful activities [133]. However, these are overarching guidelines encompassing a vast array of different technologies, main target groups and areas of support. Although the third focus area of DISTINCT lies with social participation in meaningful activities, the Best Practice Guidance does not contain a step-by-step guide on how to implement and operate social technology to facilitate social interaction and support caregiving relationships.

One set of guidelines that is more specific in both the area of use and the caregiving setting are the recommendations developed by Lazar and colleagues in 2018 [240]. These guidelines are developed to guide the successful implementation and use of digital recreational systems involving PLWD in an institutional setting. In line with relationship-centred approaches, Lazar et al. emphasised the importance of involving a facilitator (supportive person using the system with the PWLD) and evaluating how much the systems enable conversation and interaction between the facilitator and the PLWD [240]. However, these specific operationalisable recommendations are not transferable to a community-based caregiving setting. There seems to be an even larger gap in knowledge on how to guide community-dwelling caregiving dyads in the implementation and operation of social technology and to the best of my knowledge, no such guiding framework has been proposed. The barriers and facilitators identified in *Paper III* and *IV* might serve as a point of departure in the development of such a guiding framework. If technological devices facilitating social health through participation in social activities for community-dwelling caregiving dyads are to be included in health insurance schemes on an equal basis as other assistive technologies, guidelines for the implementation and operation in a home-based environment must be developed.

7.4. Implications for future dementia care policy

Policymakers and governments play and important part in facilitating the uptake of social technology among PLWD and their caregivers. With the rapid development in social technologies creating novel opportunities for technology-assisted dementia caregiving, policymakers must seek to harmonise such developments and remove barriers that can delay the integration of social technology into standard care [218]. However, facilitating the uptake of social technologies among vulnerable population groups also necessitates the safeguarding of individuals' data agency and confidentiality. Policymakers and regulators therefore play a central role in ensuring that technological solutions intended to enhance the care and independence of PLWD never, under any circumstances, undermine the autonomy and confidentiality of end-users [229, 230].

7.4.1. Regulation of data protection, privacy, informed consent

First and foremost, policymakers have the responsibility to address situations and conditions that could undermine a social, legal and ethical adoption of social technology among end-users [218]. Such user-centred involvement ensures that the needs and concerns of the target population are adequately addressed [203]. Joint efforts to increase the accessibility and availability of social technology for older adults – with or without dementia – need to be accommodated by rigorous and comprehensive data protection laws. Policymakers need to safeguard individuals' privacy and confidentiality while enabling individuals to provide informed, valid consent. This consideration is arguably even more important when employing technical solutions in vulnerable populations. These legal frameworks must also define clear responsibility, culpability and accountability for all funding-, development and implementation phases of social technology targeting PLWD and their formal or informal caregivers. The development of a legal framework for technology in dementia caregiving is a complex endeavour [237]. Therefore, as addressed by the OECD almost ten years ago: The global challenge of dementia necessitates the development of a multi-national plan that could harmonise technological development, facilitate the process of technology transfer, establish a framework for public-private partnerships for innovation, and create new models for multinational governance [241]. Considering the patchy international harmonisation of regulation of state laws [228], the requirements postulated by OECD are still highly relevant a decade later.

7.4.2. Policymakers must play their part in facilitating the uptake of social technology in dementia caregiving

In addition to ensuring a social, legal and ethical adoption of social technology among end-user with dementia, policymakers play an important part in expressing facilitating the uptake of social technology at the micro- and meso-levels. Notably, governments need to express the value of innovation and their support of promising but potentially high-risk initiatives that improve future dementia caregiving [36]. The successful development and implementation of social technologies that are useful for end-users such as PLWD and their caregivers depend on their engagement at all levels of phases, not just during short trials once the technology has been developed [36]. Policymakers must therefore advocate for and facilitate the implementation and uptake of technological solutions that may enhance dementia caregiving, both for existing and future cohorts of PLWD. Barriers identified in *Paper II, III and IV* such as limited tech literacy, user willingness and user capabilities may be mitigated by efforts such as awareness campaigns to increase the knowledge and interest around social technology, and supportive efforts to provide users with proactive and continuous support when operating novel or everyday technology. Such efforts may for instance include low threshold offers in public libraries or senior centres with seminars and workshops focusing on understanding and mastering technology.

Policymakers should also facilitate technology to promote social health and support dyadic relationships as standard offers in both institutional and community-based caregiving. As argued in *Paper II,* and echoed in this cumulative dissertation, social technology should be incorporated as standard offers in caregiving facilities to maintain social participation among PLWD and as a way to support positive dyadic interactions between caregiver and care recipient. If staff are expected to deliver socially oriented care, they need to be provided with the proper tools to do so. However, these tools seem difficult to provide as long as the end goal is not recognised as important: social health in PLWD and their caregivers. Regardless of whether one looks into barriers at the micro-, meso or macro-level, successful implementation and uptake of social technology for PLWD and their caregivers seem to face substantial barriers as long as social health is not recognised on equal terms as the physical and mental health domains. Despite growing evidence of the importance of social health for self-management in dementia, this concept is still an underestimated opportunity [33]. The body of research in this cumulative dissertation has shown the interconnectedness between social health, enrichment and relationship sustenance in dementia caregiving and the role of technology in supporting these aspects. Highlighting the concluding remarks of *Paper II;* social health must be acknowledged in dementia care policy before we can successfully implement technological solutions to promote this health domain.

Chapter Eight. Conclusion and outlook

This cumulative dissertation encompasses five published, peer-reviewed papers reporting on studies conducted to direct much-needed attention to relationship-centred caregiving in dementia, in the sphere where social health and technology meet. Furthermore, the body of work comprising this PhD thesis advocates for using enrichment in dementia caregiving in the collective efforts to shift research, practice and the public perspective toward a positive dementia discourse. The thesis revealed that to contribute to enrichment in dementia caregiving dyads, dedicated space must be provided to allow for new relationships in dementia caregiving to build and grow. Or, in the case of dyadic relationships where one dyad member develops dementia, the shared history of the dyad and their existing relationship must be sustained through support in managing and coping with the changing relational dynamics that may follow a dementia diagnosis. Social technology may be a viable source of such support.

The body of work presented in this thesis significantly contributes to the current limited empirical evidence on how social technological might facilitate social participation in dementia caregiving dyads and positively influence the caregiving relationship. For example, technology-driven solutions may support positive social interactions in dementia caregiving dyads by breaking the ice, increasing social interactions, facilitating a better understanding of PLWD, and reducing the pressure on the conversation partner. The thesis provides new evidence on the factors influencing the actual (or the hindrance of) use of social technology in a dementia caregiving context and in what ways beneficial outcomes are generated from its usage. This dissertation also provides new insights into the potential of employing social technology to support caregiving relationships and the potential impacts on clinical outcomes of both PLWD and their formal or informal caregivers. Contextual influencers of implementing such technology in this population are explored, while barriers to overcome and facilitators to promote were outlined.

This dissertation reveals that in order to support dyadic relationships and facilitate social participation in dementia caregiving, psychosocial interventions employing social technology need to take on a relationship-centred approach and develop solutions for caregiving dyads as a unit of attention, rather than considering each dyad member in isolation. The work encompassed in this dissertation further strengthens the increasingly louder voice calling for a shift in the negative discourse that has traditionally dominated dementia research and public perception, towards a more positive outlook focusing on strengths and remaining capabilities encompassed in social health.

In the “new normal” following the COVID-19 pandemic, spearheaded efforts need to be put in place to further develop psychosocial interventions promoting social health in PLWD and their caregivers. Participation in meaningful activities is an integral part of this, meaning that the severe social isolation of PLWD and their caregivers following COVID-19-related restrictions, will likely have an immense adverse impact for years to come. Keeping technological alternatives available to safeguard social health is vital in disruptive events such as a global pandemic. This requires establishing guidelines on the implementation and operation of such social technology, both in institutional and community-based caregiving. However, such practical guidance faces substantial barriers as long as social health is not recognized on equal terms as the physical and mental health domains. Hence, social health must be acknowledged as a priority before we can implement technological solutions to promote this health domain among people affected by dementia.

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Appendix A – Individual Papers

A.1 Technology facilitating social interactions between people with dementia and their caregivers

Title of Publication: Technology-driven solutions to prompt conversation, aid communication and support interaction for people with dementia and their caregivers: a systematic literature review
https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02105-0

A.2 COVID-19 restrictions, social health and the role of technology to promote social participation in nursing home residents with dementia

Title of Publication: Social Health among German Nursing Home Residents with Dementia during the COVID-19 Pandemic, and the Role of Technology to Promote Social Participation.
https://www.mdpi.com/1660-4601/19/4/1956

A.3 Social Isolation during the COVID-19 pandemic and the use of technology among community-dwelling dementia caregiving dyads

Title of Publication: Social Isolation and the Use of Technology in Caregiving Dyads Living With Dementia During COVID-19 Restrictions
https://www.frontiersin.org/articles/10.3389/fpubh.2022.697496/full

A.4 Sustaining togetherness in dementia caregiving dyads using novel technology

Title of Publication: Sustaining Our Relationship: Dyadic Interactions Supported by Technology for People with Dementia and Their Informal Caregivers
https://www.mdpi.com/1660-4601/19/17/10956/htm

A.5 Psychosocial interventions promoting enrichment in dementia caregiving relationships

Title of Publication: Enrichment of dementia caregiving relationships through psychosocial interventions: A scoping review
https://www.frontiersin.org/articles/10.3389/fmed.2022.1069846/full

Declaration

I, Viktoria Hoel, hereby declare that I have prepared the thesis without unauthorized outside help, that I have not used any sources or aids other than those indicated by me, and that I have marked as such the passages taken verbatim or in content from the works used, and that the electronic version of the thesis enclosed for examination purposes is identical to the printed version submitted.

Bremen, 8. January 2022 **Viktoria Hoel**