Gerontechnology Outcomes: Technology Intervention on Quality of Life in Dementia Care

PhD Thesis

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Aalborg, Denmark

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Gerontechnology Outcomes: technology intervention on quality of life in dementia care

Ph.D. dissertation

by

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This thesis has been submitted for assessment in partial fulfillment of the PhD degree. The thesis is supported by scientific papers and parts of the papers are used in the thesis. Co-author statements are available to the assessment committee and to the Faculty. The thesis is not suitable for publication in its present form and is intended for limited and closed circulation as copyright may not be ensured.

November 2013

This dissertation is submitted in November, 2013 to the Faculty of Engineering and Science, Aalborg University, Denmark, in partial fulfillment of the requirements for the Doctor of Philosophy degree. The public defense of the thesis will take place in February, 2014 at Aalborg University. The assessment committee consists of the following members, as decided by the Dean of Engineering and Science on May 8th, 2013:

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Machine Learning (course) December, 2009, 3 ECTS
Green energy (workshop) June, 2010, 1 ECTS
PhD Entrepreneur (course) September, 2010, 3 ECTS
BioEthics (course) December, 2010, 1.5 ECTS
How to Survive a PhD (course) March, 2011, 3 ECTS
Intellectual Property Rights (course) April, 2011, 2 ECTS
WOFIE (workshop) April, 2011, 2 ECTS
Cyber and Mobile Security (workshop) July, 2011, 2 ECTS
IPR and Innovation (course) October, 2011, 5 ECTS
Problem-based Learning (course) October, 2011, 2 ECTS
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Communication of scientific knowledge:

- 6 Presentations at 4 conferences (ISABEL 2009, ISABEL 2010, IASTED 2011, ISG 2012)
- Lectures in 3 courses (Telemedicine Techniques and Aspects 2010; Privacy and Ethical Issues in Engineering 2010 and 2011; Guest lecturer in Advanced Telecommunications 2011)
- Public speaking(long-term care facility) 2011
- 12 publications and 5 public project deliverables

[1] Carrie Beth Peterson, Anelia Mitseva, Albena D Mihovska, Neeli Rashmi Prasad, and Ramjee Prasad. “The Phenomenological Experience of Dementia and User Interface Development,” Proceedings of 2nd International Symposium on Applied Sciences in Biomedical and Communication Technologies (ISABEL 2009). IEEE Conference Proceedings: Bratislava, pages 1-5.

[2] Anelia Mitseva, Jill Harpur, Ita Brown, Natalie Magee, Anne Abildgaard, Katja Rääpysjärvi, Thomas Iversen, Carrie Peterson, Cinzia Mambretti, Antonis Litke, Georges Dafoulas, George Gorgogetas, Stavroula Souliou, Louise Andreasen, Per Franke, Carlo Gabelgaard, and Paolo Barone. ”Specification of tests and test groups,” Work Package 3, Deliverable 3.3.2(update). Public report for ISISEMD project CIP-ICT-PSP 238914, January, 2009. 119 pages.

[3] Anelia Mitseva, Carrie Beth Peterson, George Dafoulas, Areti Efthymiou, Anne Abildgaard, and Silvia Bellini. “ISISEMD Evaluation Framework for Impact Assessment of ICT Pilot Services for Elderly with Mild Dementia, Living in the Community and their Relatives,” Proceedings of Networking and Electronic Commerce Research Conference (NAEC 2010). 23 pages.

[4] Carrie Beth Peterson, Neeli Rashmi Prasad, and Ramjee Prasad. “Framework for Dementia Quality of Life Assessment with Assistive Technology,” Proceedings of the International Association of Science and Technology for Development (IASTED 2010) in Innsbruck, Austria, Biomedical Engineering Volume 1. ACTA Press 2010. ISBN: I: 978-0-88986-825-0/II: 978-0-88986-827-4. 6 pages.

[5] Carrie Beth Peterson and Neeli Rashmi Prasad. “Easy Life, Intelligent Systems, and LIFE 2.0: European Research on ICT for Aging Adults,” Proceedings of the International Association of Science and Technology for Development Conference (IASTED 2011) in Washington DC, (746) Internet and Multimedia Systems and Applications/747: Human-Computer Interaction. ACTA Press, 2011. ISBN: 978-0-88986-902-8. 8 pages.

[6] Ujjwal Bania, Carrie Beth Peterson, and Sofoklis Kyriazokos. “Leased Line via Mobile Infrastructure for Telemedicine in India,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 129-132.

[7] Samiul H Choudhury, Carrie Beth Peterson, Sofoklis Kyriazokos, and Neeli Rashmi Prasad. “A Novel Hierarchical Semi-centralized Telemedicine Network Architecture Proposition for Bangladesh,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN:.16800737. Pages 176-179.

[8] Ramesh R Subedi, Carrie Beth Peterson, and Sofoklis Kyriazokos. “Telemedicine for Rural and Underserved Communities of Nepal,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 117-120.

[9] Vikramajeet Khatri, Carrie Beth Peterson, Sofoklis Kyriazokos, and Neeli Rashmi Prasad. “A Review of Telemedicine Services in Finland,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 1-8.

[10] Anelia Mitseva, Heidi Westerby, Sofoklis Kyriazakos, Carrie Peterson, Anne Abildgaard, Jill Harpur, Katja Rääpysjärvi, Mikko Mitikka, Antonio Cimmino, Paolo Barone, Antonis Litke, Alexandros Bisogiannis, Paul Tsochantaris, Thanassis Koukoutselos, Cinzia Mambretti, Carlo Gabelgaard, and Nikos Doulamis. ”Report on validated common functional specifications building on the pilot experience.” Work Package 3, Deliverable 3.3.4. Public report for ISISEMD project CIP-ICT-PSP 238914, September, 2011. 70 pages.

[11] Carrie Beth Peterson, Antonis Litke, and Heidi Marie Westerby. “2nd Workshop (and associated material/proceedings).” Work Package 4, Deliverable 4.1.3. Public report for ISISEMD project CIP-ICT-PSP 238914, September, 2011. 11 pages.

[12] Anelia Mitseva, Athanasois Ballis, Katja Rääpysjärvi, Antonio Cimmino, Anne Abildgaard, Jill Harpur, and Carrie Beth Peterson. “Consolidated socio-economic impact.” Work Package 4, Deliverable 4.2.3. Public report for ISISEMD project CIP-ICT-PSP 238914, September, 2011. 22 pages.

[13] Carrie Beth Peterson and Antonis Litke. “1st Workshop (and associated material/proceedings).” Work Package 4, Deliverable 4.1.2. Public report for ISISEMD project CIP-ICT-PSP 238914, January, 2012. 22 pages.

[14] Anelia Mitseva, Carrie Beth Peterson, Christina Karamberi, Lamprini Ch. Oikonomou, Athanasios Mpallis, Charalampos Giannakakos, and George E Dafoulas. “Gerontechnology: Providing a helping hand when caring for cognitively impaired older adults – intermediate results on the satisfaction and acceptance of informal caregivers from a controlled study.” *Current Gerontology and Geriatrics Research*, Hindawi Publishing, Article ID 401705, 2012. DOI: 10.1155/2012/401705. 19 pages.

[15] Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. “Assessing assistive technology outcomes with dementia.” *Gerontechnology 11(2)*, p. 259. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.414.740. 10 pages.

[16] Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. “The future of assistive technologies for dementia.” *Gerontechnology 11(2)*, p. 195. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.427.742. 7 pages. Won “best paper award” at the International Society for Gerontechnology conference, June, 2012.

[17] Carrie Beth Peterson, Lars Bo Larsen, Poul Svante Eriksen, and Ole K Hejlesen. “Zarit Burden Interview shows decrease in caregiver burden with technology intervention in European dementia study.” Submitted for publication to the *British Medical Journal*. Manuscript ID: BMJ.2013.016238. 20 pages, 2014.

External research co-operation/stays:

1. Research stay at Princeton University (USA) with CTIF Global, April-August, 2011. The purpose was to inaugurate the new USA branch of CTIF and initiate research collaboration; participated in Cyber and Mobile Security Conference.
2. Attended IPR and Innovation course at Norwegian University of Life Sciences (UMB) in Ås, Norway, October, 2011. The course increased knowledge and competence in IPR and innovation through training on commercial value, IPR strategies, and skills in searching, identifying, reading, and evaluating patents and patent applications.
3. Attended International Society for Gerontechnology Maser Class in Gerontechnology in Eindhoven, Netherlands, June, 2012. The course consisted of lectures by the founders and leaders in the field. Students presented posters on their PhD work which was discussed in the course.
4. Internship with the World Health Organization Regional Office for Europe in Copenhagen, Denmark, January-March, 2013. The internship was in the Division of Non-communicable diseases and health promotion – Ageing, disability, and long-term care. The primary project included an analysis and recommendations on incorporating eHealth into the Age-friendly Cities network. Additional projects included creating a glossary of telehealth terms, bridging the Healthy Ageing programme with the E-Health programme, updating the checklist of requirements for the Healthy Cities initiative, and assisting with promotional materials for the Healthy Ageing publications.

As supervisosr for the mentioned PhD student I hereby declare that the PhD programme described below fulfills the requirements for the PhD degree laid down in the Ministerial Order.

Nov 7th 2013
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Nov 7th 2013
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Publication list

1. Anelia Mitseva, Jill Harpur, Ita Brown, Natalie Magee, Anne Abildgaard, Katja Rääpysjärvi, Thomas Iversen, Carrie Peterson, Cinzia Mambretti, Antonis Litke, Georges Dafoulas, George Gorgogetas, Stavroula Souliou, Louise Andreasen, Per Franke, Carlo Gabelgaard, and Paolo Barone. “Specification of tests and test groups,” Work Package 3, Deliverable 3.3.2 (update). Public report for ISISEMD project CIP-ICT-PSP 238914, January, 2009. 119 pages.
2. Anelia Mitseva, Carrie Beth Peterson, George Dafoulas, Areti Efthymiou, Anne Abildgaard, and Silvia Bellini. “ISISEMD Evaluation Framework for Impact Assessment of ICT Pilot Services for Elderly with Mild Dementia, Living in the Community and their Relatives,” Proceedings of Networking and Electronic Commerce Research Conference (NAEC 2010). 23 pages.
3. Ujjwal Bania, Carrie Beth Peterson, and Sofoklis Kyriazokos. “Leased Line via Mobile Infrastructure for Telemedicine in India,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 129-132.
4. Samiul H Choudhury, Carrie Beth Peterson, Sofoklis Kyriazokos, and Neeli Rashmi Prasad. “A Novel Hierarchical Semi-centralized Telemedicine Network Architecture Proposition for Bangladesh,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 176-179.
5. Ramesh R Subedi, Carrie Beth Peterson, and Sofoklis Kyriazokos. “Telemedicine for Rural and Underserved Communities of Nepal,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 117-120.
6. Vikramajeet Khatri, Carrie Beth Peterson, Sofoklis Kyriazokos, and Neeli Rashmi Prasad. “A Review of Telemedicine Services in Finland,” Proceedings of Nordic-Baltic Conference on Biomedical Engineering and Medical Physics (NBC15 2011), International Federation for Medical and Biological Engineering Proceedings Series (34) 2011. ISSN: 16800737. Pages 1-8.
7. Anelia Mitseva, Heidi Westerby, Sofoklis Kyriazakos, Carrie Peterson, Anne Abildgaard, Jill Harpur, Katja Rääpysjärvi, Mikko Mitikka, Antonio Cimmino, Paolo Barone, Antonis Litke, Alexandros Bisogiannis, Paul Tsochantaris, Thanassis Koukoutselos, Cinzia Mambretti, Carlo Gabelgaard, and Nikos Doulamis. ”Report on validated common functional specifications building on the pilot experience.” Work Package 3, Deliverable 3.3.4. Public report for ISISEMD project CIP-ICT-PSP 238914, September, 2011. 70 pages.
8. Carrie Beth Peterson, Antonis Litke, and Heidi Marie Westerby. “2nd Workshop (and associated material/proceedings).” Work Package 4, Deliverable 4.1.3. Public report for ISISEMD project CIP-ICT-PSP 238914, September, 2011. 11 pages.
9. Anelia Mitseva, Athanasois Ballis, Katja Rääpysjärvi, Antonio Cimmino, Anne Abildgaard, Jill Harpur, and Carrie Beth Peterson. “Consolidated socio-economic impact.” Work Package 4, Deliverable 4.2.3. Public report for ISISEMD project CIP-ICT-PSP 238914, September, 2011. 22 pages.
10. Carrie Beth Peterson and Antonis Litke. “1st Workshop (and associated material/proceedings).” Work Package 4, Deliverable 4.1.2. Public report for ISISEMD project CIP-ICT-PSP 238914, January, 2012. 22 pages.
11. Carrie Beth Peterson. “Integrating eHealth in the Age-Friendly Cities initiative.” Report for the World Health Organization Regional Office for Europe, Division of Non-communicable diseases and health promotion, Programme on Ageing, disability, and long-term care. Internship in Copenhagen, January-March, 2013. 25 pages.

Papers included in the thesis

A. Carrie Beth Peterson, Anelia Mitseva, Albena D Mihovska, Neeli Rashmi Prasad, and Ramjee Prasad. “The Phenomenological Experience of Dementia and User Interface Development,” Proceedings of 2nd International Symposium on Applied Sciences in Biomedical and Communication Technologies (ISABEL 2009). IEEE Conference Proceedings: Bratislava, pages 1-5.

B. Carrie Beth Peterson, Neeli Rashmi Prasad, and Ramjee Prasad. “Framework for Dementia Quality of Life Assessment with Assistive Technology,” Proceedings of the International Association of Science and Technology for Development (IASTED 2010) in Innsbruck, Austria, Biomedical Engineering Volume 1. ACTA Press 2010. ISBN: I: 978-0-88986-825-0/II: 978-0-88986-827-4. 6 pages.

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D. Anelia Mitseva, Carrie Beth Peterson, Christina Karamberi, Lamprini Ch. Oikonomou, Athanasois Mpallis, Charalampos Giannakakos, and George E Dafoulas. “Gerontechnology: Providing a helping hand when caring for cognitively impaired older adults – intermediate results on the satisfaction and acceptance of informal caregivers from a controlled study.” *Current Gerontology and Geriatrics Research*, Hindawi Publishing, Article ID 401705, 2012. DOI: 10.1155/2012/401705. 19 pages.

E. Carrie Beth Peterson, Neeli R Prasad and Ramjee Prasad. “Assessing assistive technology outcomes with dementia.” *Gerontechnology 11(2)*, p. 259. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.414.740. 10 pages.

F. Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. “The future of assistive technologies for dementia.” *Gerontechnology 11(2)*, p. 195. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.427.742. 7 pages. Awarded “Best Paper” at the International Society for Gerontechnology conference, 2012.

G. Carrie Beth Peterson, Lars Bo Larsen, Poul Svante Eriksen, and Ole K Hejlesen. “Zarit burden interview shows decrease in caregiver burden with technology intervention in European dementia study.” Submitted for publication to the *British Medical Journal*, 2014. ID: BMJ.2013.016238, 20 pages.

H. Carrie Beth Peterson. “Results from a clinical trial on gerontechnology in dementia care and caregiver quality of life outcomes.” Technical report, 2013. 8 pages.

Abstract

Given that, by and large, Information and Communication Technologies (ICTs) are aimed at increasing efficacy of workflows, faster and more accurate transfer of information, and decreasing cumbersome procedures, at least some ICTs are directed towards promoting a high quality of life. Particularly, if technologies are used to enhance services, ensure or increase safety and security, promote independence, and/or facilitate social interaction, they impact domains specifically measured in quality of life assessments. As there is no cure for most dementias, the focus of care is largely on the individual's quality of life, applying technologies to this area of health and social care would seem an appropriate fit. One of the aims of technology solutions to benefit aging adults is to improve quality of life and capability to live independently and healthily; however, improvements in life quality are difficult to measure, and showing the effectiveness of gerontechnology-based solutions is problematic.

This research investigated the quantitative data to see if technology use was indeed a facilitator of increased quality of life. The hypothesis was that the older adults and their caregivers would report a positive influence on their quality of life after using the technologies. The end users gave reports via questionnaires on quality of life while metrics, such as frequency of use of a technology and time of use were recorded through the technology system. The work is based on data collected through the clinical intervention trial, and the courses, publications, independent analysis, and interdisciplinary collaboration during the PhD study. The PhD was with the Department of Electronic Systems at Aalborg University in Aalborg, Denmark. The research has been funded through Aalborg University and the European Union Information and Communication Technology Policy Support Program Pilot Type B Project ISISEMD (Intelligent System for Independent living and SElf-care of seniors with cognitive problems or Mild Dementia). Conclusions drawn from the study show that gerontechnology can indeed have a positive influence on quality of life in dementia care; however, significant effects on life quality were confirmed only in the caregivers. There are still knowledge gaps in evaluating quality of life outcomes from using technology in dementia care, and more homogenous, rigorous studies need to be done in this field. Without careful operationalization of the concept, it will be difficult for researchers to interpret the (clinical) outcomes into meaningful results that can be used by other researchers, caregivers, and medical professionals.

Objective: Intervention analysis on the efficacy of telecare services in home-based dementia care after 15 months.

Design: Multinational, non-blinded, quasi-experimental, clinical intervention trial (nonpharmacological)

Setting: Homes of individuals with dementia in North Ireland, Denmark, Finland, and Greece

Participants: From 63 individuals with dementia and their caregivers, 31 intervention dyads are compared to 22 control dyads.

Intervention: A telecare system consisting of domotics with a centralized architecture aimed to support safety, independence, and quality of life, and to reduce caregiver burden through the transfer of tasks and care support.

Main outcome measures: Physical functioning (ADL and IADL), quality of life (QOL-AD and SQLC), caregiver burden (ZBI) are comparative outcomes, and global responses provide exploratory outcomes in the intervention group. The statistical analysis applies *t*-tests to verify significant differences in means and Pearson correlations to test for linear relationships within the data, all using 95% Confidence Interval.

Results: There is a highly significant difference in caregiver burden between the technology intervention and control groups (p=0,02**). The intervention group showed a non-significant reduction in caregiver burden (p=0,51) while the control group showed a highly significant increase in caregiver burden (p=0,01**). The intervention group shows improvement in home safety (80,6%), a high level of user satisfaction (88,7%), and the majority expresses desire to continue using (90,3%) the telecare services and a willingness to pay for such services (53,2%).

Conclusion: This study showed that the use of telecare intervention to support dementia care has protective and positive effects for the informal caregivers, but overall does not measure as performing significantly different than usual care. The evidence suggests telecare can be beneficial but methodology limitations prevent definitive conclusions.

Trial registration: The Phase I clinical intervention trial did not require registration. The trial was funded by the European Commission Competitiveness and Innovation Programme - Information and Communication Technology - Policy Support Programme. The pilot type B.2008.1.4 project ISISEMD was executed from 01/03/2009 to 31/08/2011. Reference: CIP-ICT-PSP-2-238914. Trial information can be found at the project website http://www.isisemd.eu/.

Résumé

Eftersom informations-og kommunikationsteknologi (IKT) har til formål at øge effektiviteten af arbejdsgange, sikre hurtigere og mere præcis overførsel af information, og mindske besværlige procedurer, i det mindste på et vist niveau - er IKT også rettet mod at fremme en højere livskvalitet. Især hvis teknologi kan bruges til at forbedre services, sikre eller øge sikkerhed, øge uafhængighed og/eller til at facilitere social interaktion, får den indflydelse på områder som kan måles i livskvalitetsparametre. Eftersom der ikke eksisterer nogen kur for de fleste demenssygdomme er fokus for pleje i høj grad rettet mod den enkeltes livskvalitet og anvendelse af teknologi inden for social-og sundhedsområdet kan derfor være velegnet. Et af formålene med geronteknologiske løsninger (teknologier til gavn for aldrende voksne) er at hjælpe med at forbedre livskvaliteten og evnen til at leve uafhængigt og sundt, men da forbedringer i livskvalitet er vanskelige at måle er effektiviteten af gerontechnology -baserede løsninger er problematisk at påvise.

Denne forskning har undersøgt kvantitative data for at afklare, om teknologianvendelse faktisk var en årsag til øget livskvalitet. Hypotesen er, at ældre og deres pårørende vil opleve en positiv effekt på den dementes livskvalitet ved brug af teknologierne. Brugerne gav kvalitative rapporter via spørgeskemaer om livskvalitet, accept af hjælpemidlerne og tilfredshed, mens kvantitative målinger, såsom hyppigheden af brug af en teknologi og brugstidspunktet mv. blev registreret via et IKT-system. Arbejdet er baseret på data indsamlet gennem klinisk interventionsforskning, kurser, konferencer og analyse, samt ved tværfagligt samarbejde igennem Ph.d studiet. Ph.d. studiet foregik ved Institut for Elektroniske Systemer på Aalborg Universitet i Aalborg, Danmark. Forskningen har været finansieret af Aalborg Universitet og EU Informations-og Kommunikationsteknologis Policy Support Program Pilot Type B Project ISISEMD (Intelligent System for Independent living and SElf-care of seniors with cognitive problems or Mild Dementia). Konklusioner fra undersøgelsen viser, at geronteknologi faktisk kan have en positiv indflydelse på livskvaliteten i demenspleje, dog blev en betydelig indvirkning på livskvaliteten kun bekræftet af plejepersonalet. Vores viden om evaluering af livskvalitetsresultater er stadig begrænset og mere homogene og rigide studier er fortsat nødvendige inden for dette felt. Uden omhyggelig operationalisering af konceptet, vil det være vanskeligt for forskere at fortolke (kliniske) udfald til meningsfulde resultater, der kan bruges af andre forskere, plejere og læger.

Formål: Interventionsanalyse af effekten af telebehandlingstjenester i hjemme-baseret demenspleje efter 15 måneder.

Design: Multinational, ikke-blindet, kvasieksperimentel, klinisk interventionsforsøg (ikke-farmakologiske).

Setting: Hjemmeboliger for personer med demens i Nordirland, Danmark, Finland og Grækenland.

Deltagere: Ud af 63 personer med demens og deres pårørende er 31 interventionsdyader sammenlignet med 22 kontroldyader.

Intervention: Et teleplejesystem, bestående af domotik, med en centraliseret arkitektur, til formål at understøtte sikkerhed, uafhængighed og livskvalitet, og mindske omsorgspersonens byrde gennem overførsel af opgaver og plejesupport.

Vigtigste effektmål: Fysisk funktion (ADL og IADL), livskvalitet (QOL-AD og SQLC) og pårørendebyrde (ZBI), er sammenlignelige resultater, og globale reaktioner giver eksplorative resultater i interventionsgruppen. Den statistiske analyse anvender t-test for at kontrollere betydelige forskelle i midler, og Pearson-korrelationer til at teste for lineære relationer i data, der alle bruger 95% konfidensinterval.

Resultater: Der er en meget betydelig forskel i omsorgspersonens byrde under teknologiintervention og i kontrolgrupper (p=0,02**). Interventionsgruppen viste en ikke-signifikant reduktion i omsorgspersonens byrde (p=0,51), mens kontrolgruppen udviste en meget betydelig stigning i omsorgspersonens byrde (p=0,01**). Interventionsgruppen viser forbedring i hjemmets sikkerhed (80,6%), en høj grad af brugertilfredshed (88,7%), og størstedelen udtrykker ønske om at fortsætte med at bruge (90,3%) af telebehandlingstjenesterne, og vilje til at betale for sådanne tjenester (53,2%).

Konklusion: Denne undersøgelse viste, at brugen af telebehandling til støtte for demenspleje har beskyttende og positive virkninger for de uformelle omsorgspersoner men generelt ikke lader til at performe væsentligt anderledes end normal pleje. Det peger mod at telebehandling kan være gavnligt, men metodebegrænsninger forhindrer endelige konklusioner.

Trial registrering: Fase I; kliniske interventionsforsøg kræver ikke registrering. Forsøget blev finansieret af Europa-Kommissionen for konkurrenceevne og innovation - Informations-og kommunikationsteknologi - støtteprogram . Piloten typen B.2008.1.4 projekt ISISEMD blev eksekveret fra 01/03/2009 til 31/08/2011. Reference: CIP-ICT-PSP-2-238.914. Trial-information kan findes på projektets hjemmeside http://www.isisemd.eu/.

Preface

During my undergraduate study of psychology, I became interested in cognitive neuropsychology and the processes to store and produce new memories. In particular, I was curious about individuals with neurological damage or disease, the selective breakdown of skills, and the coping mechanisms they use to reason about the world they live in. This curiosity led to a desire to work with dementia and aging adults. Following the completion of my Master's in Gerontology, I worked as an in-home caregiver to a woman with dementia (Early-Onset Alzheimer's disease). She and her husband were a huge motivation and showed me new aspects of working in dementia care; they have taught me many lessons that I continue to realize today. I have thought of them the entire time I have been working on my PhD and cannot find the words to express the deep gratitude I have for the influence Carolyn and Mike have had on my personal and professional life.

After moving to Denmark in 2005, I read a nursing article "The Phenomenology of Knowing the Patient" [1] and was inspired by the similarities with working and caring for someone with dementia. By then, I was sure I wanted to continue a career working with dementia, but had not figured out where the field was going or where I would fit in. While traveling in Mexico in 2008, I was overwhelmed by sprawling, vibrant Mexico City, and I started to think about how many people with dementia would be living here in the coming decades. In exploring future trends for aging adults, the pervasiveness of technology certainly plays a role. The motivation started in thinking about how we develop new technologies to make life easier and more enjoyable, basically, to have a positive influence on quality of life. If we are also using technologies in health and social care, the idea is that it will also have a positive effect on quality of life. In dementia care, the primary treatment is on slowing decline and maintaining or increasing QOL, and technology has strong implications to be a successful intervention strategy. A growing body of evidence shows that independent living, telecare, and telehealth solutions provide multiple options for health and social care systems to offer the elderly. Many assume that technologies *obviously* make tasks easier to carry out, but these obvious benefits need to be tested in order to determine the overall impact of health technology solutions. And the idea for the PhD was born.

Gerontechnology and quality of life in dementia care

The participants and data are derived from the multi-national ISISEMD project [2], which helped to fund the PhD study. One of the first tasks was to conceptualize quality of life in order to identify areas where technology could have a positive impact and to determine the appropriate evaluation tools. The selection of inclusion and exclusion criteria and evaluation tools were corroborated with prominent professionals in dementia care. Another major task in the beginning was the writing of the research protocol and documents related to legal issues and ethical applications. I also assisted in designing and evaluating various GUI adaptations and provided initial insight for the development of the services before being tested in the regions, including feedback gathered from a focus group and public education arrangements. Before the services were installed, I assisted in the baseline evaluations of participants in Denmark, and spent several sessions with the professional caregivers in the region to learn about the (usual) care offered, service delivery, and for more information on the participants. As I am not a native Dane, the professional caregivers were instrumental in teaching about how dementia and elder care is perceived and managed in northern Denmark. After the assessment periods (baseline, mid-term, and final), I would assist with quality checks on the data to ensure that scores were correct and within the stated ranges. The project's statistical analysis was carried out by partners who have a stronger statistics background, and I carried out an independent final analysis for the PhD after the project concluded. So, while this thesis presents a more detailed statistical analysis of the ISISEMD outcomes than have previously been published, some of the results will be different than those reported in the project deliverables and publications due to the reworking of the data.

Acknowledgments

Growing up, I spent a significant amount of time at the local long-term care facility. My grandparents were on the board of directors and staff members for many years, and my mother was a nurse there for some years. I would often visit after school and developed close friendships with several of the residents over the years; the intergenerational relationships in my youth have certainly impacted my career path. My father was an electrician, and as I started a career in health and social care, I had not imagined that his profession would influence me as well. My family has a wonderful role in my career development and support: Grandma Lillian and Grandpa Warren for their inspirational, life-long dedication to healthcare, Mom and Dad – who knew I would end up combining your professions; my aunts, uncles, and cousins who work in various branches of health and social care; the Clarks, Berry's, and Allyn's have been supportive and encouraging; and Nathan Clark - you add so much quality to my life.

Friends and others who I am thankful for their influence include: Anne Kelly, Kathi Faith, Sandy Carr, Carole Larkin, Dave Comeau for introducing me to the concept of Gerontechnology, Carolyn and Mike Macaulay, Lisbeth Møller, Charlotte Bisgaard Nielsen, Donatas Saulys, Arnas Sumila, Carles Navarro, JoanMa Palos, Mads Kim Jensen, and to Corrie McDougall for warning me that a PhD would change me forever. Special thanks to Amanda DiMaria, Nathan Clark, and Heather Reeves for their valuable feedback and editing.

My colleagues at the Department of Electronic Systems (particularly in the Networking and Security group, Center for TeleInFrastruktur, Multimedia Information and Signal Processing group, and Signal and Information Processing group) have created an exciting and enriching work environment. Special thanks go to Nicola, Carlo, Andrei, Manas, Oana, Catalina, Bayu, Pouf, Nuno, and Boyan for the sci-fi conversations that inspired me to write my first award-winning paper. My colleagues who graciously shared office space with me, especially Bilge and Antonietta who patiently answered a lot *of questions in the beginning. I would also like to thank Neeli Prasad for taking a chance on me for this opportunity to study interdisciplinary engineering. The partners in the ISISEMD project were wonderful to work with. I am particularly appreciative of those in Frederikshavn, Anne and Dorte, as well as the participants who shared their experiences with me.*

I thank the friendly, supportive staff at Aalborg University, especially Dorthe Sparre and Charlotte Skindbjerg Pedersen for their professional capabilities in helping with necessary forms and procedures. I would like to thank my supervisors Lars Bo Larsen and Ole Hejlesen for the discussions and ideas, and the thesis assessment committee for their constructive comments. I would also like to thank P. Svante Eriksen for his guidance on the statistical analysis. The colleagues and friends that I met through conferences have helped me to develop professionally and personally. It has been a wonderful experience to present my research and to share common interests through attending conferences.

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Key components in the thesis

Section/topic	#	Key component	Page
TITLE			
Title	1	Descriptive title (e.g. identifies the study design, population, intervention, etc.).	i
	2	Study design (e.g. systematic review, meta-analysis, clinical trial).	xi
ABSTRACT			
Structured summary	3	Structured summary (e.g. includes: background; objectives; eligibility criteria, participants, interventions; synthesis methods; results; conclusions; implications of key findings; and registration number).	xi
INTRODUCTION			
Rationale	4	Summary of relevant studies that examine benefits and harms of the intervention.	28
	5	Explanation of the rationale for the study in the context of what is already known.	37
Objectives	6	Explicit statement of hypothesis and research questions (e.g. PICOS: participants, interventions, comparisons, outcomes, and study design).	38
	7	Explanation for choice of comparators and the clinical relevance of efficacy and harm outcomes.	26; 54
	8	Identification of primary, secondary, and other outcomes, including the specific measurement variable (e.g. systolic blood pressure), analysis metric (e.g. change from baseline, final value, time to event), method of aggregation (e.g. median, proportion), and time point for each outcome.	58
METHODS			
Protocol and registration	9	Indication of where the trial protocol can be accessed, including registration number.	Xi; 42
Ethical approval	10	Ethics committee approval, including information on informed consent and financial or other competing interests.	42
Study design	11	Description of the study settings and countries where data will be collected.	xi; 39
	12	Description of trial design including type of trial (e.g. parallel group, crossover, factorial, single-group) and framework (e.g. superiority, equivalence, exploratory).	xi; 39
Eligibility criteria	13	Inclusion and exclusion criteria for participants (e.g., PICOS, length of follow-up) and report characteristics (e.g. years considered, language), giving rationale.	41
Sample size	14	Determined number of participants needed to achieve study objectives.	42
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	42
Search	16	Present full electronic search strategy for at least one database, including any limits used, information sources, process for selecting, etc.	26; 98
Intervention	17	Description of the intervention with sufficient detail for replication. Description of the criteria for discontinuing or modifying interventions (e.g. participant request, change in symptoms), and concomitant interventions that are permitted or prohibited during the study.	39
	18	Description of strategies to improve adherence to the intervention, and procedures for monitoring adherence.	46
	19	Description of plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects.	53
Data collection process	20	Time schedule of enrolment, interventions, assessments, and visits for participants, preferably using a schematic diagram.	53
	21	Description of plans for the assessment and collection of trial data (e.g. frequency and procedures).	53
	22	Description of plans for data entry, coding, storage, and related processes to promote data quality (e.g. double data entry, range checks).	53
	23	Description of study instruments (e.g. questionnaires, laboratory tests) and their reliability and validity, if known.	54
Data items	24	Defined variables for which data were sought (e.g. PICOS, funding sources) and any assumptions and simplifications made.	59

Summary measures	25	Stated principal summary measures (e.g., risk ratio, difference in means).	59
Synthesis of results	26	Description of the methods of treating and handling data (e.g. combining results, measures of consistency, methods to handle missing data).	53; 62
Statistical methods	27	Statistical methods for analyzing primary, secondary, and other outcomes.	61
	28	Methods for any additional analyses (e.g. subgroup, adjusted analyses)	71
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Summary of evidence	35	Summary of the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	93
Limitations or bias	36	Summary of any limitations or risk of bias that may have affected the evidence (e.g. bias at the study or outcome level, selective reporting, simplifications, and assumptions)	97; 102
Conclusions	37	A general interpretation of the results in the context of other evidence, and implications for future research.	108
FUNDING			
Funding	38	Sources of funding for the project, study, and other support (e.g., supply of data).	xi

This checklist is based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) checklists.

- Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097. Or see www.prisma-statement.org.
- The SPIRIT checklist is copyrighted by the SPIRIT Group under the Creative Commons “Attribution-NonCommercial-NoDerivs 3.0 Unported” license.

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List of acronyms

AAL – Ambient Assisted Living
AARP – (formerly) American Association of Retired Persons
ADL – Activity of Daily Living
ASDL – Asymmetric Digital Subscriber Line
AT – Assistive Technology
ATD – Assistive Technology Device
BEL – Belfast (North Ireland)
CBS – Cornell-Brown Scale for Quality of Life in dementia
CI – Confidence Interval
CSF – Cerebrospinal Fluid
CT – Computed Tomography
D-QOL – Dementia-Quality of Life
DCM – Dementia Care Mapping
DEMQOL – Measurement of Health-Related Quality of Life with Dementia
DMZ – Demilitarized Zone
DK - Denmark
DSM – Diagnostic and Statistical Manual
EP – Elderly Person
ETUQ - Everyday Technology Use Questionnaire
EU – European Union
FAQ – Frequently Asked Questions
FCG – Formal Caregiver
fMRI – Functional Magnetic Resonance Imaging
FR/FRED – Frederikshavn (Denmark)
FSP – First Step Processing
GPS – Geographical Positioning System
GPRS – General Packet Radio Service
GSM – Global System for Mobile communication
GT – Gerontechnology
GUI – Graphical User Interface
HCI – Human-Computer Interaction
HRQOL – Health-Related Quality of Life
HW - Hardware
IADL – Instrumental Activity of Daily Living
IASTED – International Association for Science and Technology for Development
ICD – International Classification of Disease
ICG – Informal Caregiver
ICHI - International Classification of Health Interventions

ICT – Information and Communication Technology
IEEE – Institute of Electrical and Electronics Engineers
IOT – Internet of Things
IP – Internet Protocol
IQR – Interquartile Range
ISABEL – International Symposium on Applied Sciences in Biomedical and Communication Technologies
ISISEMD – Intelligent System for Independent living and SElf-care of seniors with cognitive problems or Mild Dementia
IT – Information Technology
LAP/LAPP – Lappeenranta (Finland)
MAD – Median Absolute Deviation
MANET – Mobile Ad hoc Network
MMSE – Mini Mental State Exam
MoCA – Montreal Cognitive Assessment
MRI – Magnetic Resonance Imaging
OECD – Organization for Economic Co-operation and Development
OT – Occupational Therapist
PERS – Personal Emergency Response System
PET - Positron Emission Tomography
PIR – Passive Infrared
PROMIS – Patient Reported Outcomes Measurement Instrument System
PROQOLID – Patient Reported Outcomes on Quality of Life Instrument Database
QOL-AD – Quality of Life – Alzheimer’s disease
QALY – Quality-Adjusted Life Year
QOL – Quality of Life
QOLAS – Quality of Life Assessment Schedule
QUEST - Quebec User Evaluation of Satisfaction with Assistive Technology
RFID – Radio Frequency Identification
SD – Standard Deviation
SMS – Short Message Service
SPECT - Single Photon Emission Computed Tomography
SQLC – Scale of Quality of Life of Caregivers
TR – Trikala (Greece)
UN – United Nations
VIPS - Valuing people with dementia and their caregivers, treating people through Individualized care, taking the Personal perspectives of the person with dementia, and a positive Social environment
WHO – World Health Organization
ZBI – Zarit Burden Interview
ZET – Zero Effort Technology

Chapter 1. Introduction

Declining fertility rates and increasing life spans are leading to a fast growing proportion of older adults who have an increasing risk for developing dementia. The rising number of people living with dementia means that fewer family caregivers are increasingly performing complex tasks that have traditionally been carried out by paid professionals, providing considerable benefits to their family and society. Without a younger generation's volunteer caregiving, the private and public health and social care systems alone cannot meet the growing demand for long-term care.

In the 21st Century, technologies are increasingly encountered on a daily basis. Gerontechnology is an interdisciplinary field that promotes human health and well-being into old age through the use of technology. Previous studies have investigated the efficacy of gerontechnology to support dementia care. In most studies, the results of dementia care outcomes are complex to concretely interpret and methodological problems make generalizing the results problematic.

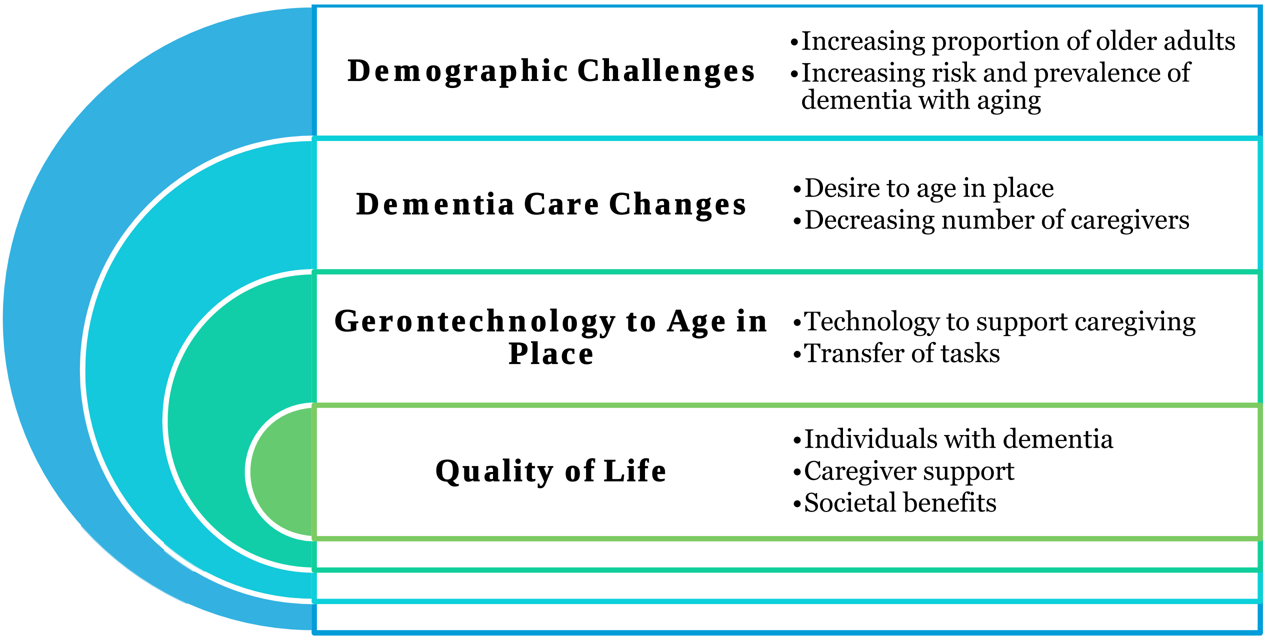
The thesis focuses on the areas of dementia care and technological solutions that can provide support in the home. The outcome of concern is if and how quality of life is affected by these. The aim of the research is to add to a growing body of evidence on technology and outcomes in dementia care. As part of the thesis, several papers are included to further emphasize on themes and issues encountered in the research. Excerpts from the papers are in the text and the full text is available in the appendix and from the publishers.

The care paradigm is changing as more people are living with chronic conditions (such as diabetes, arthritis, and dementia), and health and social care shifts focus from curing ailments to caring for individuals [3]. Without effective therapies to modify the course of dementia, intervention strategies focus on other benefits for the patient and their caregivers, largely related to quality of life issues. Gerontology (the social, psychological, and biological study of aging) finds that a significant part of the aging process involves the use of knowledge and tools to control and adapt an environment or to adapt to an environment. Gerontechnology is the interdisciplinary field that merges the sociological, psychological, and biological studies of gerontology to promotes human health and well-being into old age through the use of technology [4] [5]. Gerontechnology can assist in care provision and promote aging in place. When taking the strategy to assist in dementia care by adapting the environment with technology, the key is to allow the home to mediate in administering or managing a continuum of care that increases as functional status declines [6]. *Aging in place* is being able to age in one's own home in lieu of institutional placement [7] [8]. If Information and Communication Technologies (ICTs) are used to enhance services, ensure safety and security, promote independence, or facilitate social interaction, they impact domains specifically measured in many quality of life assessments. This suggests a higher quality of life (QOL) for the individual with dementia, a higher QOL for the caregivers, and increased quality of care (which can be measured by the technology itself). Furthermore, aging in place promotes community living, and the majority of older adults wish to remain in their own homes instead of living in a care institution [9] [10].

The field of gerontechnology is still quite young; there was little published research on gerontechnology in the late 1980s, but the field experienced a boom in the early 2000s and is now one of the fastest growing areas of research and development. The implications of such investigations influence a multitude of fields in their development and applications as well as a better understanding of the outcomes. Psychologists, gerontologists, medical professionals, manufacturers, architects, and engineers use evidence-based knowledge to help facilitate optimum living conditions for the citizens they serve. In the broader sense, gerontechnology has goals of supporting more active years in the job market, encouraging a healthy life span, reducing the digital divide by designing technologies to be more aging-friendly, and decreasing costs of living and care in old age. It is a user-driven area of research and application that connects gerontological theory with purpose-driven technology. As MP Lawton brought to our attention in 1998 [11], all humans who live to advanced adulthood will become users of gerontechnology. This PhD study applies gerontology theory to evidence-based research for the development, use, and evaluation of technologies used in dementia care. The results are used to determine if and in which ways gerontechnology can influence dementia care. The hypothesized outcomes are that the users would report a positive influence on their QOL after using the technologies when compared to a control group. The thesis concerns the thematic areas of dementia care and technological solutions that can support them; the connecting thread is how quality of life is affected by these.

Figure 1 represents these components of the thesis. It is not enough to see where technology could provide support, but to also examine how that support can be measured, thereby contributing to continued development. This research adds to a growing body of evidence on technology and outcomes in dementia care.

Figure 1 Central themes of the thesis



In Chapter 2, an overview of the issues involved is given, the rationale for the study is formed, and the state of the art in home-based dementia care is examined. The background chapter makes the case that there will continue to be an increasing demand for personalized dementia care and using technologies to this end can be beneficial. This chapter considers the global trends in population aging and declining birthrates, studying the projected increase in dementia prevalence, and investigating recommended and effective methods for dementia care. The theoretical framework used for the motivation and subsequent interpretation of the research is described, and particular attention is given to the concept of quality of life. The state of the art examins the types and methods of dementia care interventions the effectiveness of said interventions, and how they are incorporated into this research.

Chapter 3 presents the hypotheses and the research questions to investigate if technology use in dementia care has a positive effect on quality of life. The research questions narrow the scope of the research to the identified concepts and provide structure to study the postulated research outcomes. The primary question in the research is to examine if gerontechnology-supported dementia care has different outcomes than usual care, and the supporting questions help to answer this and provide a deeper examination of the outcomes.

Chapter 4 describes the development, implementation, and evaluation methods used in project ISISEMD and in this PhD study. The background chapter provides a starting point for determining which interventions have been tested before and show promise in real-life application. This influences the methodology by providing a platform for the development of the system and services, guidelines for implementing successful dementia care interventions, and care outcomes that have previously been investigated through tools known in the field. The theoretical framework helps to define which domains of quality of life could be influenced by the intervention and why, and this helps shape the care services and determine appropriate evaluation methods. Chapter 4 contains the detailed description of the research project.

The analysis in Chapter 5 examines the evidence that answers the question if one method of dementia care produces different outcomes than the other. The evaluations are from 106 participants in Denmark, Finland, Greece, and North Ireland. 62 participants agreed to test the telecare in their homes, and their outcomes are compared to the outcomes from 44 usual care (control) participants in 3 of the 4 same regions. Outcomes in physical and independent functioning, quality of life, and caregiver stress are compared between the two groups as well as examined within the groups. This chapter entails using the data from the assessments to answer the research questions and applyies theories to explain the implications of the outcomes.

Chapter 6 discusses the research as a whole, considering the methods and tools used, strengths and weaknesses of the study, and future directions in the field. The study design and research methods necessitate a discussion on the validity and generalizability of the results. This chapter also helps to guide further studies by discussing the successful and unsuccessful approaches in the research, and beneficial areas of future development.

The conclusions in Chapter 7 associate this research to the wider sphere of application, rationalizing that even though this area of research is theoretically and practically challenging, the fact is that technology is becoming ever ubiquitous and the exponential growth of its application to health and social care warrants the development of efficient, cohesive methods for measuring and interpreting the implications of its use. The appendices contain auxiliary information, comprised of details from the background investigation, the questionnaires used in the research, papers that are included as part of the thesis, and supplementary data from the statistical analysis.

Chapter 2. Background

This chapter shows that there are several issues leading to demographic challenges in providing dementia care. The data shows that there are an increasing global proportion of older adults living with dementia, and this is projected to continue growing with advancements in longevity and declining birthrates. The data also shows a declining labor force of working-age adults to provide care for the increasing number of aging adults with dementia. In this chapter, current trends and best-practices on diagnosing dementia are discussed. The theoretical framework used for the motivation and subsequent interpretation of the research is presented, and quality of life is examined as it pertains to dementia care. Investigating the recommended and effective methods for dementia care entails examining types and methods of dementia care interventions and the effectiveness of said interventions and how they can be incorporated into this research. This allows for identify the state of the art in technological solutions to address the need for increasing care. This chapter presents the formulation of the rationale for the study; there will continue to be an increasing demand for personalized dementia care and the appropriate use of supportive technologies to this end can be beneficial.

Papers included in Chapter 2:

Paper A provides a discussion on theories used to understand older adults' experiences of interacting with technology.

> Paper A: Carrie Beth Peterson, Anelia Mitseva, Albena D Mihovska, Neeli Rashmi Prasad, and Ramjee Prasad. "The Phenomenological Experience of Dementia and User Interface Development," Proceedings of 2nd International Symposium on Applied Sciences in Biomedical and Communication Technologies (ISABEL 2009). IEEE Conference Proceedings: Bratislava, pages 1-5.

Paper B describes the background study on issues in quality of life studies and identifies the domains found to be influential on QOL in dementia.

> Paper B: Carrie Beth Peterson, Neeli Rashmi Prasad, and Ramjee Prasad. "Framework for Dementia Quality of Life Assessment with Assistive Technology," Proceedings of the International Association of Science and Technology for Development (IASTED 2010) in Innsbruck, Austria, Biomedical Engineering Volume 1. ACTA Press 2010. ISBN: I: 978-0-88986-825-0/II: 978-0-88986-827-4. 6 pages.

Paper C presents a description of European projects focused on gerontechnology.

> Paper C: Carrie Beth Peterson and Neeli Rashmi Prasad. "Easy Life, Intelligent Systems, and LIFE 2.0: European Research on ICT for Aging Adults," Proceedings of the International Association of Science and Technology for Development Conference (IASTED 2011) in Washington DC, (746) Internet and Multimedia Systems and Applications/747: Human-Computer Interaction. ACTA Press, 2011. ISBN: 978-0-88986-902-8. 8 pages.

Paper E offers a discussion on MP Lawton's instrumental work in quality of life studies, discusses environment as a mediator for activity, and theoretical motives for interventions that are focused and based on the individual. This paper also contains the details of the literature search for quality of life measurement tools.

> Paper E: Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. "Assessing assistive technology outcomes with dementia." *Gerontechnology 11(2)*, p. 259. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.414.740. 10 pages.

Paper F considers the accelerated co-development of technology and society and the opportunity for technologies to support people with dementia

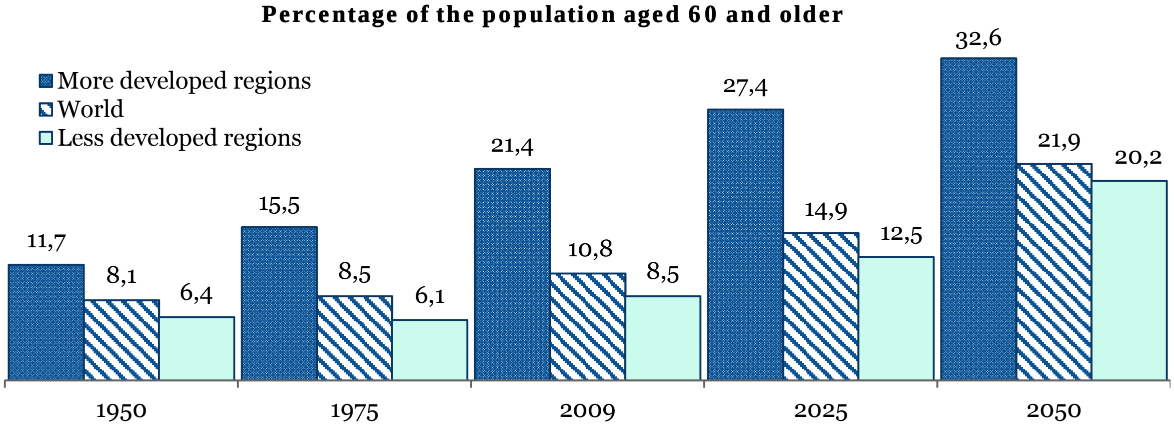
> Paper F: Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. "The future of assistive technologies for dementia." *Gerontechnology 11(2)*, p. 195. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.427.742. 7 pages.

2.1. Demographics

Population aging

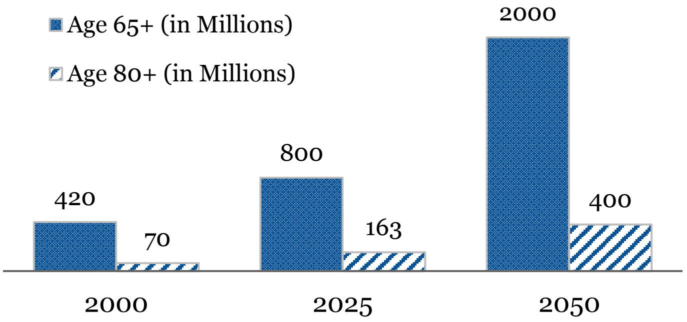
Life expectancy at birth for the world's population has increased from 48 to 68 years in the span from 1950-2010 [12], and more than 60 countries currently have a life expectancy of 75 years or more [13]. Improvements in life expectancy have been influenced by reductions in infant and childhood deaths, hygiene, and medical advances, for example to fight infectious diseases. In recent history, the main advancements have been in survival at older ages [14]. In addition to trends in increased longevity, fertility rates are declining [15] [16]. The proportion of older adults is rapidly growing, shown in Figure 2. Declining birthrates lead to fewer working-age adults while increasing life expectancies lead to higher proportions of adults living in advanced old age. In many countries, there will be more older adults requiring care than there will be adults to the available people to provide care. The United Nations Population Division summarizes that population aging is an unparalleled, pervasive, global phenomenon that is long-term, and will have profound implications for every man, woman, and child [16].

Figure 2 Global population aging 1950-2050 [17]



With declining birthrates, those aged 65+ will outnumber children under the age of 5 around 2020 for the first time in recorded history [18]. And by 2050, those over 60 will outnumber all children under age 14 [17]. With longevity, adults over the age of 80 make up one of the fastest growing cohorts around the world, shown in Figure 3. The over-80 age group is predicted to increase by 233% between 2008 and 2040 [18] [19]. The oldest populations have tripled in percentages since 1950 and comprise 5% of the total Organization for Economic Co-operation and Development (OECD) population[1] [20]. For the first time, the majority of middle-aged adults have living parents [21], and tighter labor markets are expected as the proportion of older adults will equal or exceed the proportion of taxable work force in many countries. The world's population is rapidly aging and these statistics demonstrate a broader, global need to understand aging issues and to acknowledge older adults as influential members of society.

Figure 3 Global increase in aging adults [22] [23] [24]



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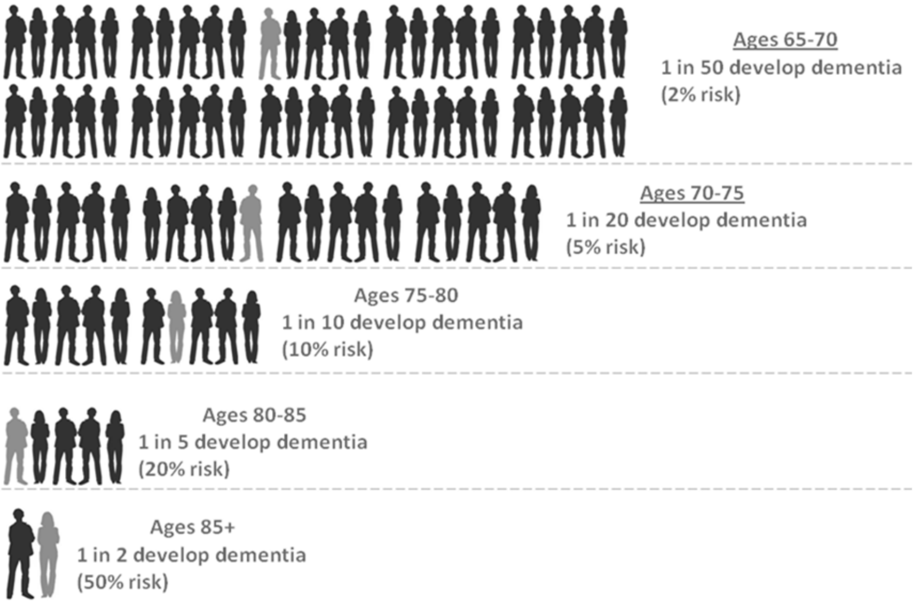
[1] OECD Countries include: Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom, and United States [356].

Increase in dementia prevalence

With population aging, one must also consider increases in disability and disease, and the resulting use of care services. Older adults are reported to consume health services at a rate of up to 5 times as much as younger cohorts [25] [26]. Yet, Grün et al. found that older adults who are not in good health, but are also not close to death, do not require any more costly care than their younger counterparts having the same conditions [27], and other studies indicate an increase in active years over 65 and decreasing number of years with severe disability [28] [29] [30] [31]. Some research shows reductions in severe disability in late life yet increases in others, and this is largely due to significant disparities in health and life expectancies across and within countries [32]. Globally, dementia is one of the main causes of disability in later life[2], and those over 85 have a 50% risk of developing some form of dementia, shown in Figure 4.

Figure 4 Risk for developing dementia (2012) [33] [34] [35] [36]



Despite inconclusive and even contradictory data on disability rates in late life[3], we do know that the aging adult population is expected to grow. One significant cost is due to the increased prevalence of individuals living with dementia. In 2010, the global cost of formal dementia care was more than 1% of global Gross Domestic Product ($604 billion[4]) [33] [37]. That figure does not include volunteer, unpaid, and family caregiving, which was valued at an additional $450 billion in 2009[5] [38]. That means that globally, over $1 trillion was spent on dementia care in roughly one year. Figure 5 shows the projected increase in individuals living with dementia. It should also be noted that up to 50% of those who would meet the criteria for a dementia do not have a formal diagnosis[6] [39], so the figures given only reflect reported instances of dementia.

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[2] According to the WHO Global Burden of Disease report, disability from dementia was higher than any other condition, with the exceptions of spinal cord injury and terminal cancer. Dementia contributed 11.2% of years lived with disability among all people 60 years and older; that is more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%), and all forms of cancer (2.4%) [359]. The societal costs of dementia were valued around €27 billion, which is almost as much as the societal costs of cancer (€14 billion), heart disease (€9 billion), and stroke (€6 billion) combined. Strikingly, as far as research is appropriated, for every €1 million in costs of dementia, around €150.000 was spent on cancer research, almost €85.000 on heart disease research, and only about €5.600 was spent on dementia research [33].

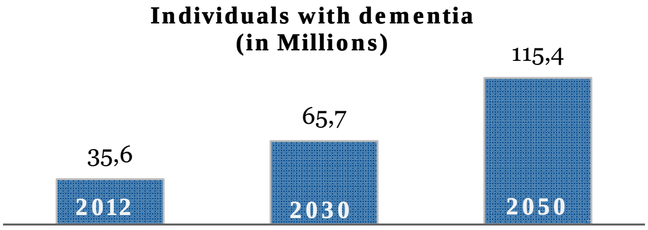
[3] [25], [354] and [355] warn against comparing health indicators as data can be derived from different methodologies and interpreted in a conflicting manner. Inconsistent and incompatible data trends show an evident need to further explore morbidity, disability, disease, and implications for aging and health resources.

[4] If dementia care was a country, based on costing over 1% of worldwide GDP, it would be the 21st largest economy, globally, ranking between Poland and Saudi Arabia [33].

[5] If informal dementia care costs were seen as company sales, it would total more than the world's largest company sales in 2009 (Wal-Mart at $408 billion) [38].

[6] This would not mean that ~100% of people over age 85 have dementia, but refers to the percentage of people who have symptoms of dementia but the type and level of cognitive impairment is not diagnosed. For example, if a 90 year old person has had multiple strokes and is showing symptoms of dementia, the family may not seek out an evaluation of cognitive functioning as they are already managing other functional issues, e.g. bathing, dressing, and feeding.

Figure 5 Projected global increase in the prevalence of dementia from 2012 to 2050 [19] [33] [40]



People are living longer than in previous generations, with more chronic conditions, and there are an increasing number of older adults living with dementia (a projected growth to 65,7 million individuals by 2030) [40]. In addressing the increase in dementia prevalence, it is beneficial to have an approximation of the labor market of potential caregivers. The data show that the proportion of working-age people to retired people[7] is rapidly declining around the world. From 2000 to 2010, the European Union (EU) experienced a 13% decline in populations aged 20 to 39 [23], and the total number of working age adults will decrease by at least another 48 million by 2050 as the elderly population increases by another 58 million in the same time span [14] [41] [42].

An individual lives with dementia for an average of 4,6 years (7,1 years with Alzheimer's disease, 3,9 years with Vascular dementia [33]); depending on age, type of dementia, and access to quality care, one can live with the syndrome over 20 years [43] [39]. Dementia is a syndrome, meaning it is not a specific disease but consists of a group of symptoms. The most common symptoms are a progressive loss of memory, cognitive functioning, and (at least one of) reasoning, language, visual-spatial processes, executive functioning, social behaviors, and personality, and the loss interferes with the performance of daily tasks [44] [45]. There are some discernible symptoms of dementia presented in Figure 6. Dementia is usually associated with aging and is the leading cause of institutionalization in older adults [34], but it occurs at any age[8]. In fact, studies show that there is a growing proportion of younger adults with dementia [46] [47] [48]. There are many different causes of dementia, which can range from dietary deficiencies to head injuries to inherited conditions to toxin exposure, and there are over 100 types of dementia [49]. Alzheimer's disease, which has disease pathology, is the most prevalent type of dementia, constituting up to 80% of all dementia cases [39]. Appendix 2 provides a description of common types of dementia, symptoms, and prevalence rates. Regardless of the cause of dementia, the syndrome will affect each individual and family differently. Each person with dementia has different expressions of their symptoms due to different personalities, experiences, and reactions to care interventions. This makes generalizing about dementia very difficult and with a higher degree of inaccuracy than when generalizing about other diseases or syndromes. As there is currently no cure for most dementias, the main focus of treatment is on maintaining or promoting a high quality of life [45]. The core components of dementia care are symptom management, slowing the rate or effects of decline, and ensuring a safe environment.

Individuals with mild impairment are more likely to have functional independence and a lower risk for imminent institutional placement, which allows for longer use of the intervention. In recruiting participants with mild to moderate dementia, one issue that arises is that many individuals do not seek out professional help or a diagnosis until the symptoms are disruptive enough that they need additional coping channels. It is a problem that it is ideal to implement the telecare technologies as early in the dementia syndrome as possible, yet difficult to access individuals in the early stages of decline. This problem warrants a discussion on the recent advancements in early diagnostics for dementias. As mentioned above, up to 50% of individuals who would meet the criteria of a dementia diagnosis do not receive one. Most people first speak with their doctor about their memory once issues are presenting a problem in daily life, but there is growing interest in early diagnosis due to dementia becoming more prevalent, particularly if there is a risk for genetic or familial types of dementia. Several national and international bodies are pushing for increased education and early detection of dementias to improve public awareness and diagnosis rates [50] [51] [52] [53] [54].

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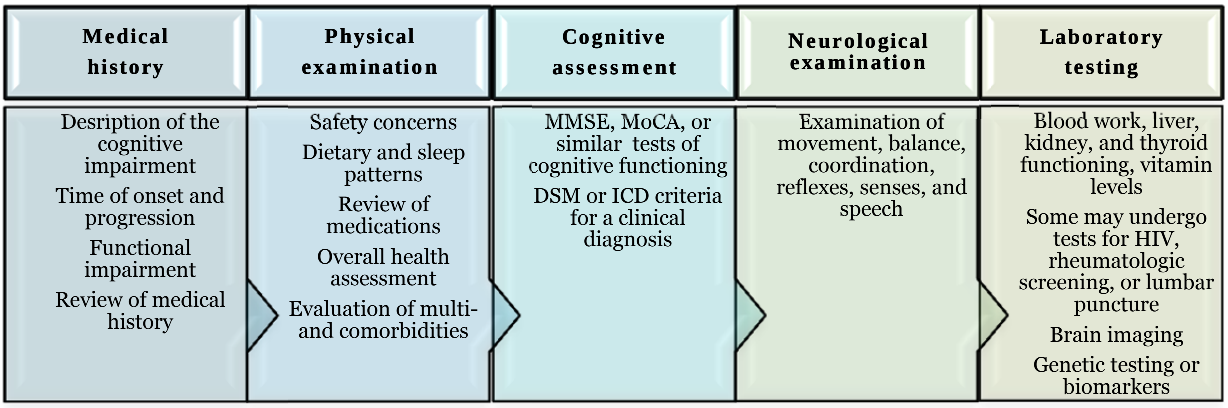
[7] The World Health Organization (WHO) has categorized ages and those belonging to the "old" segment are based on the previous retirement age in the UK. In recent years, the retirement age in many developed countries has been extended, largely due to the aging trends and lower fertility rates. In gerontology, there is discussion of changing these definitions of "old" as medical and social norms are changing and previous models of aging are becoming outdated.

[8] The youngest diagnosis of dementia I have found was a 6 year old girl (in 2008) with a rare genetic disorder (Niemann-Pick disease, type C) that leads to dementia [357].

Figure 6 Common cognition problems at the onset of dementia [55]

The two main diagnostic guidelines for dementia are the (American Psychological Association's) Diagnostic and Statistical Manual of Mental Disorders (DSM) and the (World Health Organization's) International Classification of Diseases (ICD). There is a typical process for the timely diagnosis or cognitive dysfunction or dementia [56] [57] [58], given in Figure 7. The patient meets with the doctor, who will conduct a medical history and physical exam before recommending cognitive testing. Laboratory testing and brain imaging are typically only necessary when differentiation is required for treatment or research. Early identification is most commonly achieved through neuropsychological testing (i.e. cognitive assessments), sophisticated imaging techniques (i.e. brain imaging), and biomarkers (i.e. genes).

Figure 7 Expected approach for diagnosing dementia [58]



Medical history	Physical examination	Cognitive assessment	Neurological examination	Laboratory testing
Desription of the cognitive impairment Time of onset and progression Functional impairment Review of medical history	Safety concerns Dietary and sleep patterns Review of medications Overall health assessment Evaluation of multi- and comorbidities	MMSE, MoCA, or similar tests of cognitive functioning DSM or ICD criteria for a clinical diagnosis	Examination of movement, balance, coordination, reflexes, senses, and speech	Blood work, liver, kidney, and thyroid functioning, vitamin levels Some may undergo tests for HIV, rheumatologic screening, or lumbar puncture Brain imaging Genetic testing or biomarkers

When looking at methods for early identification, the sensitivity, specificity, and accuracy of the test are chief considerations:

- Sensitivity: the true positive rate, meaning the actual positive results identified as such (correct diagnosis of dementia)
- Specificity: the true negative rate, meaning the actual negative results identified as such (correct diagnosis of no evidence of dementia)

- Accuracy: the ratio of true positives and true negatives, meaning the proportion of people correctly diagnosed by the assessment

The ideal assessment would correctly identify dementia presence and type 100% of the time; however, the sensitivity and specificity change as cut-off scores for the assessments change, resulting in a trade-off between increasing sensitivity or specificity. An accurate diagnostic tool for dementia should have a high sensitivity and specificity ($\geq$80%) [59] [60] . Of the 11 dementia diagnostic methods in Appendix 3, only 4 meet the criteria of $\geq$80% sensitivity and specificity (i.e. MoCA, CT, and PET for Alzheimer's disease, and CSF). The review of the diagnostic methods shows disconnect between trends in early diagnosis and the needed development in accurate testing[9].

It is known that older adults who are acutely admitted to the hospital exhibit cognitive impairment [61] [62], including delirium [63] (a sudden, organically-caused cognitive syndrome often exhibiting symptoms similar to dementia). Delirium occurs in up to 56% of all hospitalized patients and up to 79% of older patients who are hospitalized [64], compared to only 1-2% in the general community [65]. Full recovery from delirium is common [66] [67], and implies that screening for dementia in a hospital setting may not be the most accurate method to diagnose dementia. Additionally, the neuropsychological test results vary based on age, comorbidity, education level, and diagnostic cut-off point, so it would be irresponsible to use one test and assume it is valid for all individuals being screened. In addition to those with acute cognitive impairment or delirium, individuals with a dementia diagnosis have an average of 3 comorbidities[10] [68]. The number of comorbidities has been positively correlated with dementia severity [69], and dementia severity is a significant, independent risk factor for hospitalization [70]. There are more incidences of cognitive impairment and dementia found in hospitals or clinical settings, making them ideal locations to screen for dementia. However, an early diagnosis has a powerful impact on the individual and their loved ones, and caution should be taken as there is an increased risk for a false positive diagnosis. An early diagnosis, that is, before symptoms are noticeably present, such as in the case of families wishing to have genetic testing for their risk of developing dementia, is even more uncertain. Currently, there are no validated biomarkers for Alzheimer's disease, the most common form of dementia; without this, there is a greater likelihood of false positive diagnoses of dementia. Furthermore, the Alzheimer's Association [71] does not recommend routine clinical testing for Alzheimer's disease genes since no preventative or curative therapies are available[11]. In the case of a true positive dementia diagnosis, there is still no way to definitively tell the patient what their prognosis is for the next 1-5 years. In the 100+ years that Alzheimer's disease and dementias have been studied, there is still no single test that can definitively predict whether or not an individual will develop a dementia nor determine the progression of their symptoms. The use of biomarkers to diagnose Alzheimer's disease has not been justified, and should not be used, based on ethical and clinical rationales.

It is argued that earlier diagnosis allows individuals to better plan for their future by arranging power of attorney, advance directives, care options, insurance, wills, and estate planning. Yet it could be argued that these are key issues for all aging adults: as the risk of developing dementia is 20% in those over age 80 and 50% in those over age 85, medical professionals could easily recommend all their patients in these age groups put their effects in order without costly diagnostic procedures. Especially for older adults, would the probability of an early diagnosis of dementia be any more reliable than the general risk based on age? Furthermore, if older adults are in the hospital or visiting their General Practitioner, they most likely have multi-or comorbid conditions, and it would still be wise to advise them to arrange legal, financial, and care plans.

As Alzheimer's disease and most other dementias cannot currently be reversed or prevented, most therapies treat the symptoms and address quality of life. With the increased awareness and screening for dementia, the population is given the impression that there are effective treatments. When seeking medical help for cognitive changes, the individual or family perceives that there will be a valuable reason for doing so– and not merely a dementia diagnosis, but a plan for action to alleviate the symptoms. Awareness campaigns, although they may be successful in raising public awareness on the symptoms and resources for dementia, have also heightened public fear of dementia. Particularly among older adults and their family members, there is the fear of undiagnosed or undetected dementia, and an increasing desire to prevent or detect the dementia as early as possible. The advancement of dementia education and diagnosis is needed; however, there are also some major concerns with governments declaring dementia finding schemes that proactively screen all patients over age 75 for dementia [51] [52]. Early detection and accurate diagnosis are dependent on diagnostic criteria,

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[9] It should be noted that the data in Appendix 3 Methods to diagnose dementias, is not based on an exhaustive review of diagnostic methods, as this is not the focus of the study.

[10] Over 50% of all adults over age 65 have an average of $\geq$3 multimorbidities, and the number of multiple and chronic conditions increase with age: $\geq$4 multimorbidities in 30% of adults 65-74 years old and 55% of adults 75 years and older [358].

[11] For a description of therapies for dementia, please see Appendix 4 Dementia treatments.

which are influenced by the pharmaceutical industry (i.e. DSM[12]). New therapies being developed are dependent on early detection and accurate diagnosis for testing, and individuals who are seeking out early detection of dementia due to fear are opening a market for diagnostics to become a potentially lucrative business. The influence of pharmaceutical interests in the early detection of dementia fuels a financial stratagem in the *dementia industry* (commercial, health, and pharmaceutical industries who aim to develop products to treat dementia). There is a potential to misdiagnose and over treat patients, incurring avoidable expenses and distracting resources from individuals who have a (timely) diagnosis of dementia and a rational need to seek support [72]. Screening for dementia must be evaluated the same way as any other diagnostic screening would, and health care professionals should conduct memory assessments and referrals in an appropriate manner. However, with proactive, early screening, patients are not voluntarily being screened for dementia, since health professionals would screen patients opportunistically, effectively removing a patient's opportunity to consider their options for screening. If patients know they will be screened for dementia regardless of why they seek out clinical care, they may be likely to avoid seeking medical care when it is needed[13], which poses a significant risk to their health and well-being.

Thus far, it is not clear that the benefits of proactive screening outweigh harms, and there is no robust evidence for the benefit of early dementia diagnosis over timely diagnosis. If the expected, effective treatments are not available, will medical professionals feel the pressure to introduce new services which have no proven evidence of success? Perhaps the most convincing argument against early diagnostics is that while people at risk may be identified or diagnosed, interventions with a successful evidence-base are lacking. Here, we must ask ourselves, to what end is early diagnosis, if we cannot recommend a treatment? Are there sufficient resources to support these patients? What is the benefit of spending thousands on sophisticated imaging and biomarker detection if no course of treatment is available? Would early detection be crucial to the care of the individual? Would it even be beneficial? Particularly when giving a *probable* or *preclinical* dementia diagnosis to patients who did not seek out cognitive testing, ethical, personal, and societal consequences run high. It would seem that early diagnostic testing would largely benefit research and the dementia industry, which may not translate into benefits for the patient. Even if significant clinical evidence is found for an individual to likely develop dementia, the primary recommendation is lifestyle management. Conceivably, mental and social health liaison services will need to be better integrated in order to educate, and provide counseling for individual and family coping. There is no high quality evidence showing that it is beneficial to diagnose dementia before the patient presents symptoms and, if there is no research showing that patients are better off with an earlier diagnosis, this should not be unnecessarily forced on them. Only a clinical trial can tell if there are actually benefits for screening for dementia. Furthermore, with the projected shortage of human resources to provide dementia care, earlier and more prevalent diagnosis will tighten the demands for quality care. Clinical, medical care should practice methods that show proven benefits to enhance patient well-being, not with methods based on an opinion that it should help. The UK National Screening Committee [73], World Health Organization [33], and Alzheimer's Association [71], among others, advise that early screening should not be offered.

Demographics summary:

Declining birthrates result in fewer working-age adults while increasing life expectancies result in higher proportions of adults in advanced old age. The global phenomenon brings profound effects as many countries will have more older adults requiring care than adults available to provide care. The effects are further intensified by the growing prevalence of dementia in an aging world. Efforts are being made educate society on dementia, and to identify and treat those with the syndrome as early as possible; however, proactive screening for dementias is not recommended as the appropriate diagnostic tools are still developing and no therapies are found to be reliably beneficial.

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[12] The surprising majority (7 out of 10) of the DSM-V task force members have financial ties with the pharmaceutical industry [330].

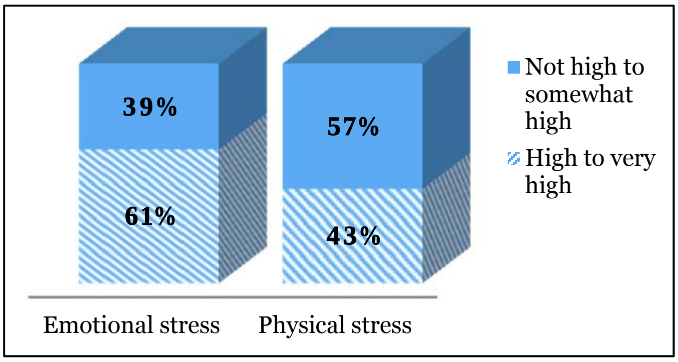
[13] An example from the ISISEMD study, the Finland region found that local residents were becoming weary of visiting memory clinics due to a fear of an Alzheimer's diagnosis.

2.2. Caregiving

In a 1989 document on research and policy on the care of older adults, the Institute of Medicine were aware of the economic, social, and health implications of caregiving, and the benefits that caregivers serve to public health [74]. The vast majority of caregiving activities are provided by informal caregivers (ICGs), who are often family and friends. Caregivers are prone to experience strain due to the demands of caregiving, often termed "caregiver burden" [75]. The act of caregiving combines the emotional expression of caring and the physical act of care providing, and both of these come into play to influence caregiver burden. Many caregivers contribute from their personal expenses to support care needs, often without financial retribution [33] [38] [76]. The American Association of Retired Persons found that 23% of caregivers cut on their own dental and preventative health care, 27% of reported a "moderate to high degree of financial hardship" directly related to their caregiving, 34% use their own savings to cover costs, and 38% diminished or altogether stopped saving for their own future [38]. Globally, annual out-of-pocket expenses for dementia care are 14% in high income countries and 50% in low income countries [33]. Aside from direct expenses on the family and caregivers, caregiving affects the economy through the paid workforce. 69% of caregivers were found to adjust their employment due to caregiving, including cutting back on office hours, changing jobs, or having to quit their job, often leading to a reduction or halt in employment benefits, health insurance, and retirement savings [38]. In particular, those who live with the loved one, are the most likely to adjust their paid employment hours [76].

Non-caregivers have better physical health, reduced risk of chronic problems, and more leisure time than caregivers. Caregiving for a person with dementia is associated with decreased immunity, slower wound healing, greater cardiovascular reactivity, reduced engagement in preventative health behaviors, and an increased risk for serious illnesses and mortality [33] [76] [77] [78] [79] [80]. Up to 85% of informal caregivers have symptoms of clinical depression, and up to 50% of that group have symptoms of major depression [38] [78] [80], and caregivers living with the person with dementia that they are caring for are exposed to more psychological problems and social isolation than caregivers who live separately [38] [38] [80] [81]. Caregivers tend to have poorer sleep hygiene, and 22% report that they are exhausted by the time they go to bed [79]. The greatest sources of negative stress contributing to caregiver burden are Behavioural and Psychological Symptoms of Dementia, such as wandering and aggression [77] [82] [83] [84] [85]. Functional decline has been identified as the most significant predictor of caregiver burden, accounting for 16% of burden [86]. A high level of dependence is a valid health outcome measure in Alzheimer's disease [87], and higher levels of caregiver burden are associated with placement of the person with dementia into formal care [78]. Dementia-related cognitive decline is one of the most common reasons for institutional placement [82]. Caregiver burden affects all facets of life and, at its worst, both physical and psychological strength is drained. Figure 8 illustrates the physical and emotional stress that informal caregivers report in the 2012 United States study.

Figure 8 Role-related stress reported by caregivers for individuals with dementia [39]



Dementia caregiving has been the most common type of caregiving represented in research literature [77], and the negative effects are frequently studied in attempts to understand and mitigate caregiver burden. While caregivers may experience social isolation, feelings of helplessness, embarrassment, and anger, caregivers also report positive effects from their role. Caregivers have reported feeling closer to their relative or friend after the diagnosis of dementia and positive feelings were fostered by the act of showing care through physical and emotional support. 55-90% of caregivers experience togetherness, sharing activities, a reciprocated bond with their care receiver, feelings of accomplishment, mastery, and personal and spiritual growth [78]. Despite the involvedness, risks, and financial drain, millions of unpaid volunteers willingly continue to provide informal care to someone with dementia and gain great satisfaction from it [38] [78].

Research has attempted to capture the essential elements of the experience of developing dementia through personal accounts and qualitative studies [88] [89] [90] [91] [92]. Evidence shows that people with dementia, even in the later stages, can maintain their identity [93] [94] [95], ability for emotional expression [96], and can convey their mood [97], and quality of life [98]. A significant part of the aging process involves the use of knowledge and tools to control and adapt an environment or to adapt to an environment. When we look at the characteristic symptoms of the syndrome given in Figure 6, we can see how living with dementia could severely impair an individual's ability to use knowledge, tools, and crafts to adapt to an environment. However, in the same light, we can see how it would be better to adapt the environment to the individual to accommodate the symptoms. There is an increasing wealth of knowledge on how to manage multiple chronic conditions for citizens: it calls for the proper coordination of care across service sectors, an optimal mix of disciplines and skill sets, and for integration, not fragmentation of knowledge and services [14] [99] [100] [101]. Coyte, Goodwin, and Laporte note that there is a growing trend in Europe in policy and practice to reduce institutional care and promote care-at-home services [99]. The American Association of Retired Persons (AARP) reports that over 90% of people over 65 want to stay in their own homes and age in place [102]. Aging in place allows individuals to proactively create their own life, connect with others, and acknowledges the influence of quality of life on individuals and the community [45]. Community living is found to defer or delay the need for public assistance and institutionalization, is more affordable and less excessive than institutional care, and supports an individual's ability to support themselves [7]. The benefits of living in the community are painfully evident to anyone who has spent an extended amount of time in a clinical setting [45]: depersonalization, immobility, and mental, physical, and economic suffering often accompany extended clinical treatment [74]. Meanwhile, aging in place enhances the positive psychological, sociological, physiological, and financial effects of aging and supports independence despite functional decline [8]. Preventing institutionalization and accommodating the public's wishes to remain at home have obvious benefits for the individual, the community, economy, and public health systems [103]. However, this also increases the need for private caregiving, both professionally and informally. Caregivers living with the person with dementia are inclined to higher levels of burden and detrimental outcomes to their own well-being. Caregiver support is necessary in order to achieve the long-term goals of individual, community, economic, and public health benefits of aging in place.

Gerontechnology can help to minimize hindrances, enhance personal abilities (including counteract facilities lost during aging and disease processes), augment the ability to provide quality care and influence research trends [104]. Technologies can automate some actions, thus increasing the independence and autonomy of the person utilizing them. Technologies can also facilitate or absorb some of the caregiving tasks from nurses and family members, and is one way to collect data about the individual, their environment, and health and care outcomes. If caregivers could use e.g. a passive monitoring system to support their caregiving, they could have more peace of mind in knowing that the home is safe and that they will be notified immediately if anything should require their attention. The Technology and Dementia in the North study examined data from 29 older adults with dementia in Finland, Norway, Iceland, Denmark, and Sweden [105]. All participants used gerontechnologies to support them in daily life, the results of which showed that technologies helped older adults with dementia to maintain daily activities and social inclusion. The work of Marilyn Cash [106] further states that the early identification of dementia makes it easier to support independence by utilizing gerontechnology tools that address personal user needs, that is, to match the right technologies for the individual.

Trends in caregiving summary:

The majority of caregiving activities in dementia care are provided by informal caregivers, often family and friends of the person with dementia. These caregivers are likely to experience strain due to the demands of caregiving, which can have lasting and holistic effects on the individual and family's mental, physical, and financial well-being. The majority of adults wish to age in place in their own homes, which is shown to provide an array of benefits; but this creates more demand for private caregiving, often falling on the families and informal caregivers. Support for caregivers is needed to attain the goals and benefits of aging in place. Gerontechnology can help to coordinate care, promote aging in place, support caregivers, and assist with independent abilities.

2.3. Theories used in the research

The theoretical foundation sets the stage to define the components to be studied and the framework in which results will be interpreted. As researchers, we use theories to build upon a body of knowledge and expand understanding, to provide a method to systematically and cumulatively assimilate data. The theories used must accurately explain a larger set of observations as well as make explicit predictions for the results of subsequent observations. In gerontechnology research, a lack of theoretical foundation essentially means that the results do not add to the cumulative body of knowledge, but produce a once-only, restricted application and significance of information. The research is vulnerable to uncertainty when the measurement tools are inconsistent with conceptual definitions and intended goals. The process of aging can be eased through the use of ICTs and gerontologists are needed in the area of technology development to inform designers how to best meet the desires and requirements for support and enjoyment [11] [107] [108]. Gerontology is over a century old and a variety of information about aging has been collected during its history. Examining the biological processes of aging provides a great deal of information about the cellular processes, aging at the molecular level, and on the pathological changes in memory formation and retrieval that occur in old age. The sociological study of aging gives insight into socio-cultural variations in aging and a framework to explain age-related health, family, and socialization behaviors. Investigating the psychological aspects of growing older contributes an understanding of concepts such as loss, wisdom, person-environment fit, and life quality. As gerontology is the social, psychological, and biological study of the aging process, gerontechnology is the applied study of how technology can be used to control or adapt an environment through the lens of the social, psychological, and biological aging processes. It provides a specified understanding of aging adults as technology users and a holistic interpretation of (health) technology outcomes.

Theories of aging

ISISEMD aimed to positively influence quality of life through an integrated prototype of services which would support independence in the home and keep the caregivers informed on the activities of the person with dementia. Selecting the tools to evaluate quality of life required considering what *quality of life* is and how the construct could be measured. This section presents the gerontology theories that are used to understand the research outcomes and to support a framework for interpreting the implications. Phenomenology it is discussed as promoting user-driven design through tailoring care services, and rationalizes that the best interpretation of quality of life and application of the telecare is at the individual level. Exponential growth is discussed as a driver in the modernization of applied technology and a motivation for gerontechnology research.

Previously, it was believed that late-life development followed a negative curve, and loss was a fundamental theme in many aging theories. However, investigations during the past few decades show that older people, on average, were continuing to live and develop just as well, if not better, than younger cohorts, and these models of social and emotional aging were reconsidered. This presents a paradox where the previous models of aging focused on loss and subsequent observations demonstrated that growing older, for many, means continued growth and development. The **paradox of aging** refers to older people coping well in old age; despite losses, aging adults maintain good mental health and enjoy valuable social relationships. **Successful aging** has been a central concept in gerontology since the 1980s. It is loosely understood as the absence of physical and cognitive impairment in old age. Loosely is noteworthy, as one review of the literature found 29 different definitions of successful aging in 28 studies, concluding that, although the majority of definitions quantify physical and cognitive functioning, there was no consensus on a definition of successful aging [109]. It has been based on a biomedical model, which precludes people with chronic illnesses from “aging successfully.” When definitions have a bias towards negative health outcomes and rely on health being *the absence of disease and disability,* there are few successful agers (15%) [110]. There is also a gap between how individuals and researchers define success: the majority of older adults (50% [111] and 92% [112]) self-rated themselves as aging successfully, yet only a stark minority (19% [111] and 5% [112]) of those would be considered successful agers when using biomedical criteria. Successful aging has also been observed among people with dementia. After interviewing 224 people with Alzheimer’s disease over a period of 18 months, successful aging was directly predicted by mental health and social relationships, rather than general health or severity of cognitive decline [109].

Discussed in the introductory chapters, advances in science and medicine have reduced the prevalence of communicable diseases as leading causes of mortality and morbidity; likewise, increasing life expectancy has also influenced chronic and non-communicable diseases accounting for a higher percentage of mortality and morbidity rates. With an increasing life span and increasing risk for chronic health conditions, one could understand why some gerontologists (e.g. bio-gerontologists) would perceive an increasing percentage of years spent with disability or disease as not aging successfully

[113] [114]. Perspectives on dementia care have seen profound changes in recent decades; the major paradigm shift was from a cure-based, medical model to a care-based, medico-psychosocial model. The **cure to care paradigm** puts emphasis on the experiences of the individual, which provides information on behavioral expressions and how the care environment influences them [3]. By adjusting the paradigm for care, new ideas for goals and treatments can be incorporated, which lead to the continued development of new methods. One example of the changing care paradigm is in applying rehabilitation strategies to palliate the symptoms of dementia, proposing continued development rather than merely managing decline.

Behavioral dependency is viewed within the relationship the person has with their environment, where the behaviors and their significance give comprehension to the global construct of dependence. **Learned dependency** could be internally fostered if the person, for example, has a fear of falling and does not dare to walk without physical support, which reduces physical ability due to nonuse[14]. This is getting closer to the model of the psychological state of learned helplessness. **Learned helplessness** can impede health interventions when the individual perceives they are unable to carry out a skilled function or successfully participate in a situation and thusly assumes that they are further unable to function in other situations. Learned helplessness is also fostered in relationship dynamics where the caregiver overcompensates for the aging adult, even for activities that they could still do themselves. As aging adults adapt to their environment, the concept that elderly increasingly rely on others to provide assistance (e.g. informal caregivers) could be partially due to the social connection that the assisting relationship provides. Margaret Baltes [115] reported that older adults who were dependent on others had more social interaction than older adults who did not. In this light, the model of learned dependency may relate to **continuity theory**. This theory states that people will continue their former lifestyles into old age by adapting behavioral strategies. Continuity theory would infer that the older adult is maintaining social activities through an adjusted strategy of engagement. The caregivers in the home can become a primary source of socialization. Baltes also presents a comparison of institutional teaching and institutional caregiving, saying that there appears an expectation of incompetence (as opposed to actual incompetence) that erroneously feeds models of long-term care: where educators modify their helping behaviors to match the student's competence level, caregivers often assume incompetence and go into efficiency mode [115]. When the environment is used as a mediator to facilitate tasks, an environment that is too responsive may overcompensate for remaining capabilities and facilitate the loss of independent behaviors. The caregiving relationship can be environmentally supportive and emotionally rewarding, but over-ambitious caregiving can infantilize the person in their environment and cause emotional harm. To truly serve the aging adult, a balance needs to be made in caregiving activities that will support the older adult without teaching them that they are unable to participate. Determining the appropriate amount of (gerontechnology) assistance also includes reassessing how technologies are fulfilling care goals and serving the individual's needs.

In gerontology, **activity theory** posits that thriving in old age would be facilitated by staying active and continuing (socialization) activities. The idea is that activities are plastic in nature, subject to transformations, which in turn spurs further transformations; the individuals adapt to and advance activities while activities also adapt and advance individuals in a cycle of co-creation. This theory is a conceptual framework by which to understand and analyze activities and their significance through the consideration of, e.g. the individual, their history and culture, the environment, motivation for activity, role of mediating artifacts, and the complexity of activities. Activity theory supports a positive correlation between activity and life quality, conversely postulating that those who do not maintain or increase activity will consequently experience a lower or declining life quality. Yet, this is not causally accurate. This theory has been criticized for marginalizing those who do not participate in activities, and for overlooking the health and economic disparities that could prevent aging adults from participating [116]. Aaro Toomla took a critical view of activity theory and formulated 5 flaws in the theory [117] [118]:

1. "It relies on unidirectional instead of a dialectical view of culture-individual relationships
2. It focuses on analyses of activities without taking into account the individual involved in the activity at the same time
3. It underestimates the role of signs and the importance of focusing on sign meaning
4. It approaches mind fragmentally, without understanding the holistic nature of mind
5. It is fundamentally a-developmental and therefore not appropriate for understanding emerging phenomena, including mind."

The **social constructivist theory** posits that technology and society co-construct each other; there is continued development between social practices and technological artifacts (both in design and in use). Susanne Bødker [119] [120]

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[14] I had worked with a woman who had senile dementia and, even though she was 98, she many times thought she was in her 70's and had recently had her hip replaced. She would say she could not walk due to the surgery, and the caregivers came up with a range of tactics to support her walking as independently as possible so as not to foster her belief that she could not do it.

made an excellent point that a new technology can only be analyzed by observing the use in the real-life context. There have been some studies that support non-interactive technologies for dementia care [121] [122], and others that support that older adults [123] [124] [125] and those with dementia [126] [127] find value in interacting with the technologies put in place for their care and safety. Two articles found that participants enjoy health robots, name them, talk to them, watch them for entertainment, and anticipate they will miss them when the trial is finished [128] [129]. This population made emotional connections with robotics as an adjusted strategy of engagement for socialization [130]. This example could also be explained through continuity theory, which would posit they continued their lifestyles of social activities by engaging with the robotic vacuums.

Phenomenology considers the basic nature of objects and events, and their perceptions in human consciousness [131] [132]. It highlights the personal experience a person has and is particularly interesting to apply to dementia care; removing a pre-defined reality and focusing on how the user defines their experiences. Anne Morris describes how participants have experienced a technological device as having a single use (realistic) as well as in relation to their perception of self (existential) [127] . This means that we do not experience technology exclusively by its predetermined design, but also by its usefulness and consequences [133]. When using technologies for dementia care, phenomenology will hold that the user's relationship with the technology is a product of the particular way they view and conduct themselves in and towards the world. Understanding the phenomenology of interacting with gerontechnology while living with dementia will be of great importance, for example, how an older adult with dementia uses a touchscreen computer versus how an engineer has designed it to be used. It is likely that there will be no one theory to guide development for and to interpret the use of technologies by people with dementia when the individual and their context provide meaning for usefulness. Paper A provides a deeper discussion on phenomenology and older adults' experiences of interacting with technology:

> **Carrie Beth Peterson, Anelia Mitseva, Albena D Mihovska, Neeli Rashmi Prasad, and Ramjee Prasad. "The Phenomenological Experience of Dementia and User Interface Development," Proceedings of 2nd International Symposium on Applied Sciences in Biomedical and Communication Technologies (ISABEL 2009). IEEE Conference Proceedings: Bratislava, pages 1-5.**
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> "Nygård [126] explains how people with dementia are conscious of their preferences and actively apply them to their choices, even if they may not be capable of describing or reflecting on them. By recognizing their motivations, conceptualization, perceptions, and employed coping strategies, we have useful information to ascertain individual needs. Morris [127] validates that participants develop their own methods of interacting, illustrated through the account of one woman with dementia who would print a blank page from her printer each morning in order to keep track of the date. This was not the intended use for installing an intricate system in her home, but such demonstrations epitomize how people with dementia can come up with innovative methods to make use of their environment for support.
>
> Participatory design techniques actively collaborate with end users throughout the design process. A user sensitive inclusive design recently put forth by researchers at the University of Dundee, addresses an array of attributes typical of people with dementia to improve customized, adaptive interfaces [134]. However, as each person with dementia is individualistic, each study dealing with the population is subject to idiosyncratic reformulations and alterations. Even traditional user-centered design methods did not provide the greatest understanding of designing for the inexperienced, cognitively impaired, older adult. Traditionally, design practices have used data and technique as their means to acquire user requirements, rather than using the design theory to permit end users to express themselves, encounter issues, and stimulate innovation [135] [131]. Working by the latter approach allows for the significance of the interaction to modify not only the design, but the value of what is produced."

Martin Heidegger points out that our current understanding of everyday technology is inadequate, with definitions limiting technology to instrumental (as means to an end) or anthropological (human activity) [136]. He states that "the essence of technology is nothing technological," and emphasizes further study of the perception of technology [137]. Activities cannot be accurately understood outside of their context, and part of the context is the mental capabilities of the user. From social psychology, we can use Kurt Lewin's heuristic explanation that behaviors are the functions of both the person and their environment, and the significance of the behavior is in the transitory context [138]. Older adults who have the lower (mental and physical) functioning also have lower fit with their environment and face the greater challenges in environmental press [139]. This involves taking a phenomenological perspective and appreciating the meaning in the context [140]. Both (mental) dexterity to use the technology and behaviors (including problem behaviors) can be seen as a temporary reaction to their context (e.g. ability, state, and environment). But this is not to take a view of quality of life and technology use that is too phenomenological so as not to be experimentally tested. Stevan Hobfoll's stress model of conservation of resources describes that the home and objects are resources whose perceived value is based on what they can provide. Individuals build, protect, and retain valuable resources, and the potential or actual loss of these resources is what is distressing [139]. He holds that an individual's locus of control is shaped by their personality characteristics, their life conditions aggravate or alleviate stress, and that socialization aggravates or alleviates stress in other resources. Paper E discusses environment as a mediator for activity further:

> **Carrie Beth Peterson, Neeli R Prasad and Ramjee Prasad. "Assessing assistive technology outcomes with dementia." Gerontechnology 11(2), p. 259. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.414.740. 10 pages.**
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> "The **environmental press theory** incorporates an individual's personal competencies (i.e. cognitive, social, physical and psychological capabilities) and their environmental demands (i.e. support or hindrances when interacting with their surroundings) [141] [142] [143] [144] [145] [146] [147] [148] [149] [150] [151] [152] [153]. This theory explains the **person-environment fit** which rationalizes that too much or too little challenge for the personal competencies result in adverse effects in response to the environment [141]; the home would serve best in facilitating equilibrium. Here, the **competence-environmental press model** [141] [152] is used to analyze the relationship between the home and functional outcomes, emphasizing that each individual person will have optimal combinations between their coping capabilities and environmental factors that will facilitate optimum outcomes. It is a model to derive the best person-environment fit through the viewpoint that the less competent a person is, the more impact the environment will have. In 1939, Lewin presented his equation for behavior to explain how nature and nurture combine to shape a person, thus to better explain the person-environment interaction [138]: $[B = f(P, E)]$

The first textbook on gerontechnology, published in 2000, gives three concepts that are central to gerontechnology as a field [154]:

I. "The dynamics of society is driven by technological developments, in particular related to information and communication technology. If older people are to remain integrated into society, technology should explicitly be directed to the fast growing segment of independent older citizens.
II. Age-associated differences in ambitions and in functioning of men and women can be met by improvements in the technological environment. Suitable information and communication tools can for example serve an ambition. A task that may seem very difficult to an older person in one situation may be easier to accomplish with suitable environmental modifications. The very idea of age grading of ambitions and of abilities cannot be considered independently of the technological environment.
III. Older citizens should remain in control of their technological environment, i.e. they should be enabled to decide what they want to be automated. This refers to the concept of the user interface between older users and useful technology."

In engineering, matrices are often used as guides for evaluation by listing factors, assigning weights, and deriving a final assessment. The gerontechnology impact matrix connects domains of activity and classes of technology use [155] [156]. Table 1 provides an example of aims and applications of telecare technologies for healthy aging, based on the gerontechnology matrix. Some of the classes of technology and domains of activity are not fully descriptive as they are currently presented. For example, prevention and engagement are grouped together as a class of technology, suggesting that one technological device or service addresses both prevention and engagement. Likewise, the domains of activity insinuate connection with life domains, which are measured in quality of life assessments. Since the field of gerontechnology is still so young, the matrix needs further development and could be used as a starting point for expansion.

Table 1 Technology support for dementia care based on the gerontechnology impact matrix [4]

Desired activity	Tasks	Domain of activity	Goal of technology
Physical, cognitive, and emotional support	Fall prevention, medication management, nutrition management, physical training and cognitive stimulation	Psychological and Physiological Health	Prevention and Engagement • delay or defer restrictions in functioning
Independence, safety, daily living tasks (ADLs[15] and IADLs[16])	Support and training activities (physical and cognitive)	Housing and Daily Living	Compensation and Assistance • compensate for loss • support remaining abilities
Movement in and outside of the home	Mobility aids, Assistive Technology	Mobility and Transport	Engagement, Assistance • promote engagement in the environment
Connect with others, socialization	Social inclusion, eInclusion, enhanced communication, foster interaction	Communication and Autonomy	Prevention, Engagement, Satisfaction
Health monitoring and prevention	Access medical records, access to medical and social assistance	Governance	Care Support • devices for physical support • organization of care
Continue to work if desired, appropriate work spaces and processes	Ergonomically designed equipment	Work	Compensation and Assistance
Learning, knowledge sharing and recreational activities	Support hobbies and leisure activities, volunteer or employment	Leisure	Enhancement and Satisfaction • enjoyment of activities

Law of accelerating returns and the exponential growth of outcomes

Earlier in this chapter, it was discussed how social constructivist theory regards technology and society as co-creating each other, and activity theory regards activity and the individual co-creating each other. Many countries will simultaneously experience a dramatic shift in their population age structures. The world is likely to be more integrated via trade, technology, and financial links, creating the potential for expanded global development. Paper F considers the accelerated co-development of technology and society and the opportunity for technologies to support people with dementia:

> **Carrie Beth Peterson, Neeli R Prasad and Ramjee Prasad. "The future of assistive technologies for dementia." Gerontechnology 11(2), p. 195. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.427.742. 7 pages.**
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> "In the era of the digital divide, we are just starting to learn how to gather and interpret information on how older adults interact with technologies. The Law of Accelerating Returns implies that with the exponential growth of technology, we realize more effective and efficient ways to execute activities and achieve knowledge [157]. Even though this is largely correlated with technology, it is not hard to imagine how other elements of life are affected as a result (i.e. health care and socialization). It is expected that future generations will be more familiar with technology; there will be more homogeneity as everyone has lived their entire lives with the influence of technology. The technology will also become more personalized to individual needs and user requirements, and social and health care services will have streamlined electronic records and communication. By then, we will have a better understanding of how humans interact with technology which can help researchers to better distinguish between individual changes (e.g. preferences, needs and mood states). Some projected future trends in technology development discussed here are in anticipation of developments in context awareness, intelligent data processing, Ambient Assisted Living (AAL), robotics, the Internet of Things and Cloud Computing."

The **Law of Accelerating Returns** speculates that through technological evolution, the increasing rate of (technological) progress throughout history will continue, and, in the future, faster and more complex technological processes can be expected [158].The law of accelerating returns supports an explanation of how technology, society, and practice become increasingly entangled in an escalating number of ways, and it will become more difficult to draw distinctions between them. The accelerating progress of technology would also mean the accelerating progress of socio-

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[15] Activities of Daily Living (ADLs) consist of self-care tasks, including: Personal hygiene and grooming; dressing and undressing, independent eating; functional transfers (getting into and out of bed or wheelchair, getting onto or off toilet, etc.); continence; and ambulation (walking with or without use of an assistive device such as walker, cane, crutches, or wheelchair).

[16] Instrumental Activities of Daily Living (IADLs) are not necessary for fundamental functioning, but promote an individual's ability live independently and include: housework; medication management; finance management; shopping; use of telephone or other communication; use of technology; transportation within the community; meal preparation and eating.

cultural meaning and in shaping people’s lives. When smart phones were first created, this was a great technological breakthrough, and phones could carry out functions we previously could only imagine (mobile video conversations, touch screen interfaces, etc.). Only a few short years later, these smart phones have a wide range of applications (e.g. internet access, passive health monitoring, and location-based services) and implications (i.e. data eavesdropping, GPS, privacy). When the application of these technologies also continues to grow, the proper utilization of information gathered from eHealth, video from public security networks, smart homes, and smart cities could lead to a wealth of benefits for individuals and communities. In sum, the use of a technology grows exponentially, in all directions at the same time: processes and information both expand.

Exponential growth is related to gerontechnology in that there is an accelerating rate of technological development and processing power. Technologies become more pervasive and data can be gathered, interpreted, and used at accelerating rates. Not only are there advancements in the development of technology, but there are continued societal advancements in the use of technology and in the information it provides. However, particularly in the area of health technologies, the evaluation and interpretation of outcomes of using such technologies is accelerating at a much slower rate. The technologies that have previously been tested in residential dementia care occurred in less-understood circumstances than technologies being tested now. The context of the ability, experience, and interpretation of the results is different because the technology, service development, and understanding of implications have changed based on the interpretation of previous results. By the time we have an understanding of how the care situation was influenced, the technology has continued to evolve – things are changing so rapidly that previous frameworks may not be a reliable guide.

Theory discussion and summary:

This chapter described the theoretical foundation for the research, highlighting gerontology theories and how they relate to technology use among aging adults, in dementia care, and the continued development of health care technologies. Technologies continue to evolve, despite understanding the implications of their use still lagging steps behind. Accelerated exponential growth also poses challenges in understanding the implications of integrating technology further into social and health care services. This type of scientific investigation does not stand alone in the classic sciences (does it function?) nor is it alone in the arts (how and in which ways does it function?). Multiple factors are examined in order to evaluate whether or not technologies in dementia care increases the quality of living in a home setting. Multidisciplinary studies play a central role in understanding aging and dementia behaviors, the relevance of home care for quality of life, and integrating and evaluating technologies in caregiving.

Sometimes scientists cannot explain the presented problems and the research runs into unpredicted or undefined areas when there are inadequate explanations for the information within the current paradigm. At this point, the understanding of the scientific study is primed for a revolution, when the previous paradigm is no longer suitable to explain the scientific knowledge. Kuhn contends that the change to a new paradigm cannot be founded on logical reason alone [159]; rational knowledge is not the only valid knowledge, and usefulness is one way to enhance the intervention evaluation [160]. A specific paradigm, such as the bio-medical view of health, provides exponential growth until the methods outgrow the paradigm and it must shift, i.e. to the medico-psychosocial model of health. In the new paradigm, we can still build upon knowledge from the old paradigm and exponential growth continues. The increasing prevalence of multidisciplinary collaboration will further the scientific revolution as explanations found in one field of science could be influenced and described by another field of science.

2.4. Quality of Life

With motivation taking basis in the understanding that technology serves to maintain or increase the quality of living, one must go back to the basics and investigate what *quality of life* means and how it can be studied. Particularly when focusing on people who have dementia, the meaning becomes even more perplexing. This section first explores the concepts associated with life quality and how they relate to dementia, and then connects technology to quality of life. In studying whether or not technologies have a positive influence on quality of life in dementia care, one must have an idea of how technologies influence aging and quality of life. As this section will show, there have been divergent definitions of quality of life and how it could be measured and interpreted in dementia care. Improvements in QOL are difficult to measure and showing the effectiveness of interventions is problematic without careful operationalization of the concept.

Relative deprivation will assert that individuals determine what they have, desire, and are deprived of when comparing to other people as the standard[17]. On a personal level, relative deprivation theory asserts that perceptions of life quality are more likely to be based on one's expectations for their own life in comparison to themselves and others than to be based on biological needs. Relative deprivation theory is also used to explain why caregivers often report lower quality of life for the person with dementia than the individual themselves, in that they compare the person with dementia's life now to what it was before and against their own life now. When incorporating proxy reports of the quality of life of a person with dementia, it is important to consider how the proxy is interpreting this concept: is it from the viewpoint of how they would feel if they were in the other person's situation or how they view the other's situation from their current standpoint, or how they think the individual themselves would answer? This also brings up the issue of self-evaluating life quality: is it how the individual determines others are living or relative to their individual life history and expectations? The extent to which selfhood or identity is preserved has been an important focus in many observational studies, and results show that manifestations of selfhood persist even in severe dementia [93] [94] [161] [162]. Phenomenologists will argue that quality of life is largely dependent on the individual and how they make interpretations and perceive their individual life. As Robert Ziller [163] reasons, QOL should be approached "through the eye of the experience: a phenomenological approach."

Quality of life does not have one formally agreed upon definition; as a result, most researchers cite the World Health Organization, who created their definition back in 1994 [164], or create their own definition. The WHO [164] defines QOL as "the individual's perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards." By definition, it is the individual perception that is represented, thus assessed, in a measurement. Here, one can see that a distinction of what is considered an *individual perception* is required in order to separate data from that which is sought after and that which is not.

It is not uncommon that different measures (e.g. UN, Economist, and OECD) are quantifying different domains. QOL is an elusive concept that is not well defined, which makes research in the field more difficult, particularly in demonstrating construct validity. Because it is not well defined, quality of life could easily be misconstrued into something that the general public no longer understands to be the general meaning. To illustrate how the definition of quality of life can change the evaluation and interpretation of the concept, take the example of Denmark being rated as having one of the world's highest quality of life ratings [165] [166]. In the Economist report [165], nine domains that were based on life satisfaction surveys were used to determine a national quality of life score. While reading them, keep in mind how closely they would come to your own definition of quality of life, and how relatable they would be to someone with dementia.

1. Health: Life expectancy at birth (in years)
2. Family: Divorce rate (per 1,000)
3. Community: Rate of church attendance or trade-union membership
4. Material well-being: GDP per person
5. Political stability and security: Political stability and security ratings
6. Climate and geography: Latitude, to distinguish between warmer and colder climates
7. Job security: Unemployment rate
8. Political freedom: Political and civil liberties
9. Gender equality: Average male and female earnings

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[17] Likewise, in a consumer-driven society, relative deprivation could easily be distorted if significance is placed on societal expectations, such as having the latest technology. Materialistic deprivation aside, this theory may be a more modern version for current times where technological advances have accounted for many basic securities and the societal focus on development is towards high quality psycho-social returns.

While there would be some agreement on the importance of these domains, particularly to a nation, it is also clear that these are not universal, particularly at an individual level. Trying to investigate the multidisciplinary nature of being a human through the dimensions of socialization, economic level, health, etc. seems to imply the philosophical view that humans are an accumulation of all the stated dimensions, self-reflective, and capable of independent actions. And although it may indeed hold true that a human's life can be measured through the stated dimensions, it also needs to be considered if this is to interpret a longitudinal view of their life quality (e.g. for care assessment) or a snapshot of their life in one point in time (e.g. to rank a population).

Reductionism claims that a concept can be reduced to one or more items or ideas if all of the statements about the concept can be applied to the items or ideas. So a complex concept (i.e. QOL) is reduced to the sum of its parts and can thusly be understood by defining the individual components (i.e. domains) separately. Health-related quality of life (HRQOL) has been seen as one of the foremost tools used to measure needs satisfaction in relation to health and health service provision. Despite being widely used, HRQOL is unsatisfactory as a measurement concept as the focus is on health states, which are prone to decline through the aging process, plus health is a limited predictor of life quality, and certainly not the only influential factor in long-term care. Furthermore, generic HRQOL assessments often are not written for use by people with dementia and do not accommodate the cognitive impairments, meaning this population must rely on proxy reports to evaluate their HRQOL. Within the field of HRQOL, Quality Adjusted Life Years (QALYs) are used to denote health gains in regards to service allocation at the general level (e.g. politically and economically motivated), not necessarily to evaluate care outcomes for an individual. One issue with the QALY is that measurement scales are often created for or used in clinical settings in attempts to derive which factors of a disease or disability most affect life quality and in which ways. For example, nausea may have a lot of weight on HRQOL for those who have cancer, but not the same for those who have dementia. Proponents state that QALY values are based on information gathered from public surveys and are therefore representative of the whole population [167] [168]. However, John Stuart Mill [169] might likely find this "the tyranny of the majority," as public surveys do not necessarily represent the whole population and most certainly do not represent a minority population (i.e. those living with dementia). Furthermore, research has found that subjective quality of life has more importance than a low probability of disease, showing older adults rating themselves as aging successfully despite the objective health criteria not being met [112].

In 1982, Carl Cohen made note that merely listing domains of quality of life is not enough to measure life quality; we do not know all the important domains to consider, their weight on QOL, nor how they interrelate with eachother or unknown domains [170]. This is additionally problematic when adding technologies to factors that affect quality of life;these are prone to change over time with new cohorts of aged adults, further research in psycholgoical and sociological effects of aging and living with dementia, technologies that are integrated into daily life, and so on. Diverging from a reductionist philosophy, **humanistic** psychology holds that humans supersede the sum of their parts and cannot be reduced to components. In humanistic interventions, the therapist must have the ability to take the view of the client and view the world through their eyes. It means the therapist must ignore their external frame of reference and take care not to come across as the authority. Taking a non-pathological view, and conveying empathy and unconditional positive regard for the patient are paramount. Gestalt therapy, rooted in humanistic psychology, lays focus on the transient present state, ignores preconceptions, and is attentive of non-verbal cues as indicators of emotions. Dementia care interventions that take a holistic view of the person may be more effective in enhancing QOL, but interventions that can reduce the concept of QOL into measurable terms may provide more robust outcomes.

Mark Rapley discusses the concept of QOL and its use in measuring the success of larger paradigms, including technology development, policy, services such as care and education, and modernization of society [171]. To influence the modernization of society, quality of life is best applied at the population – not individual – level [172]. Policy is made at the national and international levels based on quality of life, such as the World Health Organization's Health 2020 policy framework [173]. It is increasingly being used as a scientific, measurable term – a goal to attain, and has become the focus of numerous policies. However, these policies do not necessarily address conceptualizing quality of life or how it can be measured. Perhaps because quality of life is such a difficult idea to define and measure, it is seen as a notion that can be used with the general public understanding its general meaning. But, if it is not defined, how will we know when we've attained our goal? If there is no agreement as to its definition, and problems in relation to measurement, can improved QOL be a sensible goal of research and policy initiatives? By trying to assess QOL at the individual level, the seriousness of the deficiencies in its conceptualization in evaluation methodology becomes apparent. It could be that measurement tools for quality of life are too simplified or too multifaceted to show any measurable effect, and the concept emerges as so complex that one is left wondering "Is 'quality of life' a meaningless term?" Despite the macro issues, it must be kept in mind that the goal of this thesis is not to present a concrete conceptualization of the meaning of quality of life but to give an assessment of how QOL was influenced by technologies in dementia care. This research takes the view that, in dementia care, it is the individual that matters (i.e. QOL at the point of care), taking a bottom-up approach to understand the concept at the individual level, from large enough groups of individuals, before generalizing the effects. Paper E offers a discussion on MP Lawton's instrumental work in quality of life studies and theoretical motives for interventions that are focused and based on the individual:

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> "Although the WHO is the main authority cited for defining QOL, there has been incongruence in how QOL should be defined and discrepancy in the theoretical basis of how that can be measured; this presents obvious issues in determining how to view QOL and effectively assess it. MP Lawton [174] recommended a hierarchical view that holds behavioral capabilities and subjective life quality as central divisions and psychological wellbeing as the desired outcome [175]. Lawton's conceptualization of QOL in dementia has thus far been the most prominent influence in the development of disease-specific instruments and many of the tools are modeled after his constructs. Lawton's work is influential here in that he proposes the environment as a criterion or facilitator to achieve psychological well-being, yet Jonker, et al., [176] report that there is a lack of research that presents a paradigm to explain the underlying correlations between QOL and the domain of home environment.
>
> With the intentions of using AT in the home to increase life quality, the authors recognize several perspectives. One is the subjective experience of the individual whose QOL is being assessed (e.g. the person with dementia), another being objective measures (e.g. biological outcomes, closer related to HRQOL) and finally the subjective perception of the proxy individual (e.g. physician or caregiver). Formerly, researchers thought it was impossible to ask the persons with dementia to accurately rate their QOL due to the nature of cognitive impairment and perceived lack of insight; therefore, proxy ratings of patient QOL were the focus of development. Fortunately, later research has shown that those with dementia can still convey their wishes and desires about their life quality to caregivers and researchers [98] [177] [178] [176] [179] [180]. Current theoretical modeling emphasizes incorporation of the individual view of QOL by directly asking older adults with cognitive impairment what is important to them in life quality and why [181] [177] [182] [183] [184] [185], which also shifts the theoretical paradigm of QOL towards individual perceptions and desires. Although it proves most beneficial to directly ask the older adult with dementia about their QOL, the proxies bring another dimension to the understanding of the situation and care outcomes; they are certainly not discouraged to give reports of QOL, but they are no longer the primary source of QOL information."

Wisdom is known to be a powerfully influential variable on life satisfaction [186] [187]. One aspect of wisdom in old age is the ability of persons to accept limitations and death as fundamental aspects of human life; they are thus more likely to report satisfaction with their lives despite objective (i.e. medical) criteria showing poorer life quality [188]. Wisdom has been studied and identified among people with dementia, however with cognition being a key component of wisdom, there are discernible differences between wise older adults and wise older adults with dementia. One study finds that individuals with dementia tend to have significantly strong (loss-based) negative attitudes towards aging than those without dementia, and that this negative attitude can intermediate between the individual's level of insight and self-reported QOL [189]. The authors conclude that negative attitudes towards aging have a direct impact on the person with dementia's self-report of quality of life. Older adults report optimism, socialization, successful coping techniques, and community involvement as more significant to successful aging than the objective (physical and mental) health criteria, and subjective quality of life has been strongly correlated with resilience, confidence, emotional and mental strength and similar psychosocial protective traits [110] [190] [191] [192] [193]. This further supports the paradigm shift in separating predictors of successful aging and good life quality from objective health states. Definitions of successful aging and of objective health states tend to define success by the judgment of others (i.e. proxy) by omitting the perceptions of the aging adults, and focus on functioning and health state as success criteria. This would put many older adults in the "unsuccessful" category: older adults have a higher risk for the prevalence of disease or disability than younger cohorts [110] [194] and defining life quality primarily based on health would inherently assume older adults have lower quality of life than younger cohorts.

It is accepted that functioning can indeed increase with age and in old age. Physical and mental health and psychosocial functioning can improve and also serve to protect as age-associated wisdom supports coping strategies in late life, which can in turn lead to increased health and psychosocial functioning. In studies focusing specifically on brain growth and dementia, the neuroplasticity of aging still exists [195] [196] [197]. This may also provide insight into why dementia symptoms have such a wide range from person to person. Different people will perceive different levels of quality on the same subject, and this can become even more problematic when one of the people has cognitive impairments. Research, however, finds that people with dementia can not only form and convey their subjective opinions (even into late stages of dementia) [178] [181] [198], but that they often rate their own quality of life more accurate than their proxy [45] [177] [181]. Several articles report interviews with individuals with dementia on quality of life domains that are important to them, allowing the target population to identify and define what would constitute a good life quality [177] [181] [182]. Those found to be most influential are: affect, self-esteem and self-image, social contact, attachment, (physical and mental) health, enjoyment of activities, sense of aesthetics, security and personal privacy, being useful, financial situation, self-determination and freedom, and spirituality [140]. Another article reports that the most influential factors for the individuals with dementia are mood, (engagement in) pleasant activities, and ADLs, and the most important domains for caregivers are mood, (engagement in) pleasant activities, and physical and cognitive functioning [199]. The self-reported influential domains of quality of life are further described in Paper B.

Many patient-based outcome measures consist of questionnaires that are subjective in nature. Objective outcome measures risk overlooking the individual patient and their real-life implications by combining data in order to quantify costs and prove benefits to a reasonable degree of certainty. There are many issues with defining the concept of and in evaluating quality of life [45]. One administration hindrance is that the methods are pen-and-paper and conducted in person, which makes the evaluation subject to interviewer influence. The metrics used to interpret the results can present analysis problems, as determining the (e.g. clinical) significance of having a better quality of life is difficult. Researchers need to be aware of the issue that increased human contact (i.e. technicians installing and maintaining systems, nurses and social workers conducting interviews and observations, scientists procuring results of the trials, media carrying out interviews which aid in dissemination, etc.) also has an influence on end user quality of life. Having others come into the residential dwelling, expressing a deeper personal interest in the person with dementia, their family and caregivers, and reaffirming the contribution that they are making to science unintentionally influences the end users[18]. The individual who is the focus of the care may be happy that a person is visiting with them and may answer more positively than then normally would, or they may be agitated by the people and the bustle in the house, and that transient mood is captured as data. It is well known that interviewer bias is found when care staff or researchers conduct assessments in person, and can lead to arriving at conclusions *post hoc ergo propter hoc*: the misinterpreted deduction that technology alone must be the variable influencing QOL.

The awareness of interviewer bias serves as support to develop and standardize quality of life evaluations in electronic form so as to reduce administration factors (i.e. environment, setting, other persons, etc.) as well as to be administered consistently and longitudinally. Evaluations in this context are important because assessing quality of life outcomes can also supplement evaluations of technology as a treatment intervention. Collecting assessment information on the intervention and QOL digitally and over the Internet provides an effective method for meta-analyses on multiple groups and in diverse locations. For more discussion of the need and development of an electronic OQL assessment to be used in dementia care, please see Papers A, B, E, and F. This would have remarkable implications for Randomized Controlled Trials, longitudinal and ethnographic studies, and to increase the ability and reliability in evaluating gerontechnology outcomes [200].

The WHO is developing an International Classification of Health Interventions (ICHI) to provide a common tool to statistically report health interventions [201]. Although ICHI does not have a specific focus on quality of life outcomes, classifying health interventions, including health technologies, is advancement in the right direction. The National Institute of Health is funding a group to establish a domain framework to analyze clinical treatment outcomes, the Patient-Reported Outcomes Measurement Information System (PROMIS[19]). [202] [203]. Likewise, the Patient–Reported Outcome and Quality of Life Instruments Database (PROQOLID[20]) group, developed and managed by the Mapi Research Trust, aims to make patient-reported outcomes as well as quality of life assessment tools available for clinical use and study [204]. Both are striving to provide structure and evidence for clinical decision making and will be valuable as health technologies continue to develop. These classifications and databases are further described in Paper E. If services are well designed with the end user in mind, Assistive Technologies (ATs) can positively impact general as well as specific domains of quality of life. As there is no cure for dementia and medications offer only marginal positive effects, it is easier to affect quality of life than it is to affect the progression of the dementia. Once quality of life is understood from a theoretical point of view, and the influential factors (domains) are identified, the next step is to determine a method to measure this concept. An appropriate evaluation for the study addresses Assistive Technology and quality of life

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[18] Unintentionally is used in the sense that although the intentional goals are to maintain or improve QOL, it is intended that this is through the use of technologies in the home, not through the researchers involved in the study.

[19] PROMIS is a system of assessment tools that measure patient–reported health status. http://www.nihpromis.org/default

[20] PROQOLID aims to identify and describe instruments to choose appropriately and facilitate access to them. http://www.proqolid.org

outcomes in home dementia care. A literature search will identify an appropriate QOL assessment tool. First, the inclusion and exclusion criteria are defined before beginning the literature search:

Inclusion criteria:

- Dementia-specific
- Assesses quality of life
- Incorporates the individual with dementia's assessment
- Is specific to technology by having been tested with telecare intervention

Exclusion criteria:

- Is not dementia-specific
- Does not assess quality of life
- Does not incorporate the individual with dementia's assessment
- Does not allow for technology intervention or has not been tested with telecare intervention

The key words to describe to the assessment in the literature search includes the terms "quality of life," "dementia," "telecare," and so on, as described in Paper E. Five assessments (QOL-AD, CBS, D-QOL, DEMQOL, and QOLAS) were all found to be dementia-specific, assess quality of life, and incorporate the individual with dementia's assessment. These five met all of the inclusion criteria except being specific to telecare.

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Particularly when working with a person with dementia, it is much easier for care providers to affect QOL than it is for them to affect the course of the disease process, which is highly individual. As mentioned earlier, one of the focus areas in measuring QOL is in assessing the efficacy of treatment; the idea is that if we assess QOL, then we are also a step closer to better assessing AT. This section presents current QOL outcomes measurement tools relevant to ATs for dementia care. The Cochrane Library Collection supports systematic reviews of health care outcomes; specifically, the Patient Reported Outcomes (PRO) methods group is interested in "health status, quality of life, adherence to treatment recommendations and satisfaction with treatment" [205]. The Cochrane search for "Alzheimer's Disease," "dementia," "quality of life" and "Health Technology Assessment" resulted in 3 documents. One was on pharmacological interventions, one as a proxy report and the last on neuroimaging techniques. Health and QOL Outcomes (HQLO) [206] is an open access, peer-reviewed journal that disseminates information on Health-Related QOL. The HQLO search for "technology" and "dementia" resulted in 19 documents, all of which were related to severe dementia, frail elderly, other conditions than dementia, and other assessments than straightforward QOL. The Patient-Reported Outcomes and Quality of Life Instruments Database (PROQOLID) [207] was also searched for "Alzheimer's Disease" and "dementia," which resulted in a total of 22 instruments, none of which are administered via computer or in electronic format.

- 7 were designed for caregivers alone, excluding self-reports by person with dementia
- 10 tested other measures than QOL, such as memory or apathy
- The 5 remaining, all modeled after Lawton, include:

1. QOL-AD – Quality of Life in Alzheimer's Disease [178] is a questionnaire answered by the person with dementia and caregiver separately and weight is given to the older adults responses but it is not AT-specific
2. CBS – Cornell-Brown Scale for Quality of Life in Dementia [208] is a semi-structured joint interview with the person with dementia and their caregiver, if discrepancies in responses occur, weight is given to the proxy and it is not AT-specific
3. D-QOL – Dementia Quality of Life Instrument [180] is an mixed interview and questionnaire self-report but is not AT-specific
4. DEMQOL – Measurement of Health-Related Quality of Life with Dementia [209] is another interview-based tool that is not specific to AT

5. QOLAS – Quality of Life Assessment Schedule [210] is also interview-based for the person and their caregiver which can be tailored to fit the individual but is not AT-specific

- No tools were found to be dementia-specific evaluations of QOL *and* allow for AT influence.

As no assessment met all of the inclusion criteria, this indicates an area for the future development of a dementia-specific QOL assessment tool that is valid for telecare interventions. Regarding the five tools, the reported psychometrics provide further information on their use, reliability, validity, and other indicators that aid in determining which will be the best suited for this study. Based on information gathered during the literature search, Table 2 provides the metrics that aid in interpreting quality of life results.

Table 2 Metrics of the assessment tools that evaluate quality of life in dementia care

Tool	Domains	Scoring	Consistency and reliability	Validity	Other
Identification of the assessment and primary source of information	*Which concepts are measured as influencing QOL*	*How QOL is rated*	*How consistent the tool is across items, in similar conditions, between raters, and across administration points*	*To what degree the tool accurately measures QOL*	*Additional information on the tools to help guide decision-making*
QOL-AD Quality of Life in Alzheimer's Disease **[178]**	13 domains of physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores around the house, ability to do things for fun, money, and life as a whole.	13 items rated on a 4-point Likert scale (1 = poor, 2 = fair, 3 = good, 4 = excellent) Range of 13 to 52, where higher score = higher quality of life.	Internal consistency reliability is good for both patient (α=0,84) and caregiver reports (α=0,86). Internal reliability is good (α range0,88 to 0,89). 1-week test-retest reliability intraclass correlations is 0,76 for patients and 0,92 for caregivers.	Validity was supported by the correlation of higher QOL-AD scores with lower depression levels, better day-to-day functioning, and higher activity level. Patient-caregiver internal validity (r=0,40, p<0,01) [98].	QoL-AD is, internationally, the most widely used quality of life measure for people with dementia [211]. Incorporates patient and proxy assessment and gives weight to the patient responses [212].
CBS Cornell-Brown Scale for Quality of Life in Dementia **[208]**	5 domains of mood, ideational disturbance, behavioral disturbance, physical signs, and cyclic functions.	19 items rated on a 5-point scale with positive and negative poles (-1=mild or intermittent, -2=severe or chronic, 0=neither positive or negative, +1=mild or intermittent, +2=constant).	Good internal consistency reliability (α=0,81), and inter-rater reliability (intraclass r=0,90).	Criterion validity through a positive correlation between QOL scores and visual analogue mood ratings (Spearman's ρ=0,63).	Reliability and validity were not adversely affected by patient cognitive impairment. Incorporates patient and proxy assessment.
D-QOL Dementia Quality of Life Instrument **[180]**	5 domains of positive affect (6 items), negative affect (11 items), feelings of belonging (3 items), self-esteem (4 items), and sense of aesthetics (5 items).	29 items , plus one global item ("Overall, how would you rate your quality of life?") on a 5-point visual scale.	Internal consistency reliability range α 0,67to 0,89 (acceptable median α=0,80). Two-week test-retest coefficient range α 0,64 to 0,90 (acceptable median α=0,72).	Convergent validity by correlations with Geriatric Depression Scale scores and DQoL sub-scales (r=-0,48 self-esteem, r=-0,61 positive affect, r=-0,64 absence of negative affect, r=-0,42 feelings of belonging) [180].	Only incorporates the assessment by the person with dementia.
DEMQOL Measurement of Health-Related Quality of Life with Dementia **[209]**	5 domains of daily activities and looking after yourself, health and well-being, cognitive functioning, social relationships and self-concept).	28-item DEMQOL 31-item DEMQOL-Proxy	Patient DEMQOL internal consistency is good at α=0,87 and test-retest reliability range is acceptable to good (α range 0,76 to 0,84). DEMQOL-Proxy internal consistency range is good to excellent (α range 0,87 to 0,92) and test-retest reliability is good at α=0,82.	DEMQOL-Proxy is moderately correlated with the age of the person with dementia, but not of carers.	Not appropriate for those with MMSE<10 (severe dementia).
QOLAS Quality of Life Assessment Schedule **[210]**	Persons with dementia rate 2 constructs per domain out of the 5 domains of physical, psychological, social/family, work/economic, and cognitive. Each domain has a maximum score of 10.	The person with dementia rates the extent of their problems on a 6-point scale (0=no problem, 1=very slight problem, 2=mild problem, 3=moderate problem, 4=big problem, and 5=it could not be worse). Scores range 0 to 50 with higher scores reflecting poorer QOL.	Internal consistency reliability is acceptable at α=0,78 for patients and caregivers.	Acceptable criterion and construct validity.	QOLAS is the only dementia-specific tool that is tailored to individuals and uses both qualitative and quantitative measurement. Caregivers nominate QOL items they feel are most important for the person with dementia and assess how they perceive the QOL of the person with dementia to be.

Quality of life summary:

The work in the field of quality of life research has been limited in its philosophical basis (i.e. reducing an end user to a disease or disability and related outcomes) and application (i.e. provision of services but not necessarily a better understanding of the disease or disability). It could be said that many quality of life tools, but particularly HRQOL tools, promote the dualistic view of good versus bad, meaning that the measurement will essentially imply that the person has good or poor life quality rather than seeing quality of life as a neutral and plastic concept. Ann Bowling [213] further illustrates this point by saying that researchers who have constructed HRQOL assessment tools rarely have the philosophy or theoretical background to soundly support their work and are not so concerned with discussions and conflicting views of what “quality of life” means to individuals and groups. It is not sufficient to use one theoretical perspective to understand this multifaceted research – quality of life and gerontechnology involve multiple theories, as do health and social care.

Research in the area of health and care technologies is advancing, including studies to enhance or evaluate dementia care. Technology systems are being commercially developed and offered, and individuals and health organizations are already using them, despite a weak evidence-base to support clinical decision-making. Perhaps it is because these technologies seem to have such apparent use, that consumers are likely to take up use. Sometimes the simplest uses of ICT have such an obvious benefit, that they easily achieve widespread adoption [214]. An example would be PERS alarms, e.g. a Person Emergency Response System pendant that is worn and pressed if the person should require assistance. These are easily and quickly implemented, yet a standardized assessment is often lacking, and the full effects (personal, social, medical, economic, or otherwise) may not be realized. Promoting a humanistic (psychosocial) approach to dementia care could be misinterpreted (or misused) to justify a consumer-based approach to developing gerontechnology. In fact, the two approaches may have similar goals, but a consumer-based approach would focus on the possibility of increasing quality of life through increased choice of services, and a humanistic approach will focus on what shows evidence for increasing quality of life through meaningful, individual outcomes [215]. The former takes a macro view of quality of life and the latter takes a micro view. There is no evidence to make a clear conclusion on whether one approach is different than the other in achieving outcomes, but the psychosocial approach is focused on in this thesis. Access to ICT-supported services will broaden innovation chains, but appropriate evaluation methods need further research and development for the full scope of use to be realized. Incorporating individual preferences is not a new concept in dementia care (person-centered) or in matching technologies with the person (consumer-based). This has greatly aided in the understanding of quality of life and its influential domains and dimensions, serving as a basis for future research. However, it is difficult to integrate personal inclinations into quality of life assessments as the dementia-specific measurement tools are generalized. With a foundation for conceptualizing individual quality of life, now that we are living in a digital age where technologies are increasingly personalized, it is apposite to include individuation in quality of life.

2.5. State of the Art in gerontechnologies for dementia care

Once the evaluation tools have been identified, the next step is to be able to evaluate the effectiveness of the technologies through longitudinal, real-life application. Assistive Technologies and complex technology systems have a strong potential to positively influence quality of life [216]; context-aware technologies that utilize sensing and machine learning can autonomously perceive the environment, learn from the context, and adapt to the user, carrying out predefined, goal-directed tasks in real-time [200]. They can aid in tasks that require learning and decision making (two characteristic limitations in dementia). Current high-tech technologies[21] can connect best practices in caregiving to supportive and enhancing technologies. This thesis does not strive for nor advocate gerontechnology replacing human caregiving practices in dementia care, but to add to an evidence-base for determining technologies which can supplement dementia care and accommodate demographic trends that necessitate changes in health care provision. A range of long-term services that are adaptable to address the emotional, physical, and mental stresses of dementia care are needed. Formal care services are most supportive when they are tailored to the unique challenges of dementia and recognize that the dementia caregivers' experience is different when compared with other caregivers [38] [78] [82] [217] [218] [219]:

- Interventions aimed at individual caregivers *and* their families, including the care receiver, are more likely to relieve caregiver stress than those targeted just at caregivers.
- Allowing caregivers to co-create the interventions by identifying problems to be addressed, methods to address them, and the timing and frequency of the interventions are more likely to achieve desired outcomes than interventions that are fixed in terms of what, how, and when they are delivered.
- Multi-component interventions are more effective in relieving stress and burden than interventions that have narrower strategies and goals.

Technologies for in-home dementia care

Advancements in ICT allow for sophisticated solutions to be incorporated into telecare[22]. Telecare is currently in its 3rd generation [220] [221] [222]. The first generation consisted of devices used to activate alarms; these technologies required a user to activate them (e.g. PERS pendants). The second generation of telecare included sensors and detectors that were used to monitor the care environment parameters (e.g. biosignals or fall detectors) and automatically transmit data to the care manager. The third generation of telecare adds wireless and multimedia technologies to support virtual care through e.g. GPS locating or ambient intelligence. Some commonly used high-tech technologies include [200] [223]:

- *Communication* technologies allow connecting with others, sharing information, and communicate about the environment (e.g. real-time alarms, access to telecare networks).
- *Robotic* technologies are increasingly popular and can perform duties such as domestic services (e.g. vacuum or assistance with toileting), or companionship activities (e.g. robotic pets).
- *Home automation* technologies monitor and ensure home safety (e.g. fire alarms, automatic doors).
- *Sensors* can monitor and collect data (e.g. motion detection, temperature, radiofrequency transmitters, user recognition).

As mentioned in relation to social constructivist theory in section 2.3, some studies on robotics and aging adults have found that the older adults would form social and emotional bonds to the robots: naming them, talking to them, or finding entertainment through watching the robotic vacuums. For more on this, please see Paper F: The future of assistive technologies for dementia. For a more detailed description of comparable European projects, please see Paper C: Easy Life Intelligent Systems, and LIFE 2.0: European research on ICT for aging adults, and Paper G: Zarit Burden Interview shows reduction in caregiver burden in European dementia study.

Telecare can support access to services and provide new methods to provide care. One intervention strategy is to support care by transferring tasks from the individual to the telecare system. When aiming to transfer tasks from human caregivers to services through technologies, the technology needs to carry out tasks that were previously performed by humans. When combining State of the Art technologies with the best practices for dementia caregiving, it is important to

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[21] Low-tech interventions include handrails or ergonomic tools such as walkers, and are not expanded upon in this work.

[22] It should be noted that gerontechnology applied to aging adults living with dementia is the focus in this research, as encompassing all ICTs and Assistive Technologies would be too broad. The technologies and services that are evaluated are done so with the design and benefit of the aging adult in mind. Health technologies that are designed for other user groups (i.e. care management such as electronic health records) are beyond the scope of this thesis.

remember that the best care is provided when the individual symptoms of dementia are appreciated. The Alzheimer's Association manual, "Dementia Care Practice Recommendations for Professionals Working in a Home Setting" [224] describes best practices for in-home dementia care and highlights six core recommendations:

1. Recognize the signs of dementia and behavioral indicators and to detect changes
2. Communication with the person with dementia and their family as well as coordination with other care providers
3. Apply and assess nonpharmacological methods to the care plan through person-centered techniques
4. Encourage proper nutrition and hydration
5. Medication management
6. Manage home safety issues

In person-centered care, the person is considered the authority in their life history and needs, and the therapist or intervention facilitates in meeting the needs of the individual [225]. The humanistic and phenomenological philosophy of psychologist Carl Rogers's person-centered therapy was first applied to dementia care by Tom Kitwood [226]. The transient state of quality and the individual's views on participating in their own lives are respected and supported, and maintaining personhood is the primary aim of dementia care support [227]. Person-centered or relationship(dyad)-centered care have become key theoretical models associated with quality dementia care as they accentuate the history, personality, habits, and preferences of the person rather than solely addressing the medical or behavioral state [228]; the dyad are viewed as the experts on the situation. An application of person-centered dementia care to interventions focused on communication skills is based on the VIPS model (Valuing people with dementia and their caregivers, treating people through Individualized care, taking the Personal perspectives of the person with dementia, and a positive Social environment). One study reporting on the VIPS model in a long-term care facility finds the intervention is highly feasible, and that the depersonalization of people with dementia decreased while empathy and hope increased among the caregivers, and caregivers used more specific communication strategies [225]. Another method that systematically applies person-centered care is the Dementia Care Mapping (DCM) Method [229]. It was originally developed to be used as a clinical tool in dementia care, and has gained popularity in quality of life research as well [230]. DCM is perhaps better designed for assessing components of both quality of care and quality of life through academia than through practical application due to complex scoring (including inter-rater reliability) and time consuming methods (recommended 6 hour observation) [231]. Studies have reported underdeveloped evidence on reliability, but find good face validity, and acceptable concurrent validity of the DCM with clinical outcomes (pressure sores) and quality of life proxy scores, [232]. However, further research is needed to grow the evidence-base. The DCM checklist allows raters to record the frequency of indicators of well-being [233]:

1. Being able to assert one's own will and desires
2. Being able to show a range of emotions, including pleasure and sadness
3. Initiates contact with others
4. Showing self-respect
5. Enjoying humor
6. Showing pleasure
7. Being able to relax
8. Being helpful
9. Has signs of ill-being
10. Has distress or despair
11. Has intense anger
12. Has physical discomfort or pain
13. Has fear or anxiety

Gerontechnology encompasses a wide range of technologies, with the primary stipulation being that they are focused on aging through their design and use. While not a theory in itself, the gerontechnology impact matrix helps to categorize the type of technology and activities they support. The gerontechnology matrix is not used to evaluate gerontechnology interventions or to assign weights to QOL domains. Essentially, a QOL domain could connect with each technology separately or with multiple technologies, depending on the use of the technology. For example, one person may use their hearing aid to listen to the television (compensation and assistance) whereas another may use it to participate in social situations (engagement), and both uses are related to the enjoyment of activities (enhancement and satisfaction). It was not a goal of the research project to address all areas of activity identified by the matrix, but this is a good exercise to see which domains of life are focused on. Technologies for dementia care are only part of the scope of gerontechnology, and individuals with dementia comprise only a portion of aging adults. As this research combines both elements, it is important to address the classes of gerontechnology and how they contribute to healthy aging with dementia [4] [155] [234]:

1. Prevention and engagement – delay or defer restrictions in functioning and promote user engagement in their environment, monitor to prevent additional problems (e.g. games, such as Nintendo Wii, motion-activated lights to prevent falls).
2. Compensation and assistance – compensate and assist with shortcomings due to the aging process (e.g. increased lighting when reading or large buttons on a mobile phone).
3. Care support and organization – physical support (e.g. lifts for transferring) and organization (e.g. medications management) used for self-care and provided caregiving.
4. Enhancement and satisfaction – services to enhance the enjoyment of activities, and reinforce new activities (e.g. ambient lighting, music, virtual reality, and social activities).

While it seems straightforward to connect the recommendations for dementia care with appropriate gerontechnology, it proves complex to connect the practice of dementia care with the self-reported domains of quality of life that have been identified as highly desirable. Technology has the ability to facilitate matching QOL domains to dementia care, thus supporting dementia care provision. Table 3 presents examples of appropriate gerontechnology interventions that could match the recommendations for the home care environment. This table is based on information first presented in Paper B. The technologies can encompass various uses and produce multiple outcomes, and the ones presented are offered as examples.

Table 3 Self-reported quality of life domains, recommended care practices, and related gerontechnology

Self-reported QOL domains	Aspects of dementia care	Technology intervention	Class of gerontechnology
Affect	**Ability to recognize the signs of dementia and to detect change** • Positive influence • Foster expression of emotions	• Ambience, e.g. music to alleviate symptoms of Sundowner's syndrome • Machine Learning builds upon patterns of interaction and detects changes in behavior (e.g. increased night wandering)	**Enhancement and Satisfaction**
Self-esteem and self-image	**Apply and assess nonpharmacological, person-centered methods to the care** • Viewed as a person contributing to their life • Endorse intact abilities • Promote self-care	• Independence-enabling technology, e.g. reminders for meal times • Electronic calendar; • Technologies can be tailored to the personal care plan	**Compensation and Assistance**
Social contact	**Communicate with the individual, their family, and coordinate with care providers** • Develop and maintain social relationships • Foster interactions with family, friends, and society	• Videophone to encourage socialization • Online social networking • Robotic companions • Mobile and fixed devices (e.g. email, video conference, mobile phone)	**Engagement** **Enhancement and Satisfaction**
Attachment	• Feeling imbedded in home and community • Reinforcing social and familial bonds	• AAL to promote the environment as a place to feel relaxed and useful • GPS tracking to allow safely enjoying surroundings	**Engagement**
Health (physical and mental)	**Proper nutrition and hydration** **Medication management** • Discourage being viewed as a person with disabilities • Reduced environmental barriers • Document behavioral and somatic symptoms	• Electronic medication dispensing systems • Cognitive stimulation through games • Access to patient records through eHealth • Biomedical sensors • Smart refrigerators can determine if food is being eaten regularly	**Compensation and Assistance** **Care support and Organization**
Enjoyment of activities	• Provide a range of interesting activities • uphold decision-making about activities	• Ambience control, e.g. lighting • Offer activities for pleasure, e.g. digital pictures	**Engagement** **Enhancement and Satisfaction**
Sense of aesthetics	• Familiar situations • Promote comfortable atmosphere • Appropriate level of stimulation	• Ambient Assisted Living, e.g. temperature, music • Reduce distractions in the environment, e.g. adjust lighting to reduce glare	**Enhancement and Satisfaction**
Security and personal privacy	**Manage home safety issues** • Peace of mind by reducing anxiety • Ensure physical safety • Facilitate privacy	• Motion sensors for wandering alerts • GPS locating outside the home • Accelerometers for fall detection • Actuators shut off stove • Automatic door locks	**Prevention** **Care support**
Being useful	• Promote using skills retained • Encourage participation in household activities	• Electronic calendar with reminders for tasks and activities • Robotic vacuum, e.g. supplement cleaning	**Engagement** **Enhancement and Satisfaction**

Known outcomes of interventions in dementia care

Previous research on outcomes in dementia care interventions has shown promise for the ability to positively effect factors that are found to influence QOL. Cognitive stimulation programs show significantly improved mood, memory, cognitive functioning, and reduced behavioral disturbances when compared to controls [235] [236] [237]. Studies show that behavioral treatment interventions result in 40% more significant improvement in depression when compared to controls [238] [239] [240] [241] [242], reduces the frequency and duration of nighttime awakening by 32%, significantly increases exercise, and significantly reduces depression [243]. Interventions focusing on exercise and behavior management find that over 80% of caregivers can successfully learn to guide patients in exercise, and the intervention results in significantly more exercise, better general physical functioning, fewer restricted activity days, higher quality of life, and fewer depressive symptoms at 24 months [244]. In a preliminary exercise-based intervention for cognitively impaired adults who live alone, after 9 weeks, participant results include attending 90% of classes and increasing mean exercise time by over 170 minutes per week, increased physical functioning, general health, emotional well-being, and significantly improved cholesterol [199]. Environmental modifications and problem-solving strategy interventions show significantly reduced frequency of problem behaviors and significantly lower caregiver distress when compared to controls after 12 months [245] [246], and significantly reduced agitation [247]. Environmental-based skill building has significantly reduced ADL decline, improved caregiver skills, effect, and affect, and has reduced behavioral problems and caregiver distress from behavioral disturbances when compared to controls [248] [249] [250]. A multicomponent environmental (physical and occupational therapy and home modifications) and behavioral intervention (problem-solving and care training) for older adults with chronic conditions shows that intervention participants have fewer hazards in the home, less difficulty with ADLs and IADLS (specifically bathing and toileting), less fear of falling, higher utilization of adaptive strategies, and improved self-efficacy [251]. Occupational therapy (OT) interventions have been shown to influence significantly higher levels of positive affect and self-care independence, and significantly lower levels of caregiver burden after an average of only 2 months [252]. Compared to controls, participants with dementia who receive OT interventions functioned significantly better in ADLs and their caregivers report feeling significantly more capable in dealing with dementia after 12 weeks [253]. Activities and interventions involving music are also gaining popularity in dementia research, showing that music can foster engagement in activities, promote empowerment, support social and emotional bonding, and enhance the enjoyment of activities [254]. Even in people with severe cognitive impairments, the presence of and involvement in music can increase quality of life. Additionally, support group interventions, while often reported to show mixed outcomes, has been shown to significantly decrease family conflicts and result in improved quality of life (including less decline) [255].

The non-technological interventions show promise in dementia care, however, the scientific literature on technology interventions for dementia care reveals the need for further research and development in this area. In evaluating the outcomes of gerontechnology interventions in non-institutional dementia care, there are several primary areas of consideration:

- The *effectiveness* of the intervention is the ability to achieve desired outcomes (e.g. influence quality of life),
- The *efficiency* of the intervention is the ability to effectively use the intervention (e.g. technology use matches the best practices in dementia care),
- The *efficacy* of the intervention is the ability to produce the desired effects (e.g. a functional intervention that positively affects quality of life), and
- The *satisfaction* with the intervention within the predefined context (e.g. usability and user acceptance of and satisfaction with the intervention [256]).

Research shows that the most important benefits that technology provides to caregivers are in saving time (77%), easing care logistics (76%), safety (75%), increasing feelings of effective caregiving (74%), and reducing stress (74%); caregivers will be most interested in technology interventions that will support them in delivering, monitoring, tracking and coordinating care [76]. Authors often state that the results are skewed by the heterogeneity of the population (e.g. age, gender, education level, symptom expression, etc.), varying methodologies (e.g. aims, intervention components, study design, and outcome measurements), or are too premature to generalize [33] [78] [257] [258] [259] [260] [261] [262]. One review found that most studies demonstrate feasibility only or have small sample populations, and finds no evidence on the effects of smart home technologies on health outcomes, and that the evidence for the clinical impact of technology use was insufficient [263]. In one international study, the caregivers of 233 individuals with Alzheimer's disease watched a 5-minute video on an (upcoming) ICT system designed to support the independent living of people with dementia. The study reports that 66,4% of caregivers thought the ICT system could improve quality of life, care (56,1%), safety (87%), monitoring (80,7%), medication management (87,4%), environment (85,2%), and communication (83,4%) [264]. They further find that the ICT is perceived most useful for people with moderate dementia, aged 75-84. One study from focus groups finds that the primary concerns of caregivers are in maintaining roles, relationships, and lifestyles, and ensuring the safety of the person with dementia [265]. In a follow-up focus group, the caregivers were shown a demonstration of an Internet-based monitoring system which includes cameras, sensors, a portal to view activities, and automatic messaging to mobile phones. They report that the caregivers reacted positively to the monitoring system and agree that the technology could be helpful in managing their primary concerns. The study goes on to report on the installing and evaluating a monitoring system for dementia care in the homes of 19 families after 24 weeks [265]. They discuss the importance of training the users, disruptions associated with technical issues, and describe the caregivers' evaluation through open-ended questions. They report that the participants felt the benefits of the technology outweighed the problems, and 86% responded that the monitoring system made life easier, 79% answered that the system positively affected how the caregivers spent their time, and 19% report the system had positive influence on the dyad relationship. They also find that 44% replied that the system made life more difficult, and equal numbers found positive and negative effects in relationships with other family members (13%) and with friends (6%). One study examined a commercially-available monitoring system in the homes of 14 adults with dementia over 9 months [266]. The authors report improved safety and security, reductions in caregiver burden, financial benefits, and demonstrates the potential of monitoring and early warning systems to maintain aging in place. Another study focusing on caregivers of people with dementia finds the literature to reveal that Assistive Technology can support independence and increase quality of life in the dyad, delay or defer institutionalization, and promote safety [267]. They utilized focus groups of caregivers to investigate their conceptions of technology and conditions for incorporating the technology. The caregivers are found to take a utility perspective on the technology, and the results show positive attitudes and readiness among the caregivers regarding the use of Assistive Technology; however, there is concern among the caregivers that technology can oversimplify tasks and weaken intact abilities (e.g. learned dependence) and that there is stigma of visible technologies in the home, especially among younger old adults.

A systematic review on environmental control systems and smart home technologies (not specific to dementia care) identifies only 11 out of 1739 studies could be included for analysis, and those studies have small sample sizes and wide diversity [268]. They find limited effects in IADLs remaining stable in intervention groups, increased independence and ability to perform activities, increased satisfaction with activity performance and control over the environment, improved social activities, improved quality of life, increased psychosocial function, feelings of self-worth, and happiness, and satisfaction with the control systems. The authors conclude that although the technologies seem promising and should be considered, evidence is lacking and no collective outcomes could be extracted. An investigation of the clinical significance of dementia caregiver interventions (not exclusively technology-based) finds that the interventions largely consist of psychosocial, environmental, behavioral, and pharmacological interventions [262]. The clinical outcomes investigated include symptomatology (e.g. changes in depression, hostility, anxiety, physical health, blood pressure, exercise, needed level of care, number of prescriptions), quality of life (e.g. life satisfaction, social activities, caregiver burden), social significance (e.g. the impact on society and service provision), and social validity (e.g. the acceptability of the intervention and impact). The authors find small to moderate improvements in symptomatology and mixed positive effects on quality of life (depression, stabilizing benefits for anxiety, distress, anger, hostility, and physical health), social significance (differential rates of institutionalization, mixed results on service utilization and time spent giving care), and positive outcomes in social validity (80-100% of participants report the intervention as having positive value). 16 of 33 studies report a positive impact on caregiver burden, ranging from 1,5%-14% improvement when compared to controls, while 17 of the studies find no effectiveness of their interventions on caregiver burden. The authors summarize that in some caregivers, significant reductions in caregiver burden can be achieved. They conclude that accrediting specific outcomes to direct causes is challenging as most interventions are multifaceted and have methodology problems, and there is still no consensus on significant levels of change for the results to be considered meaningful. The capacity to improve overall quality of life is reported as small; however, specific attributes of global quality of life show positive outcomes and assessing multiple outcome indicators (e.g. mood, social support, coping strategies, burden, or marital satisfaction) may provide a more comprehensive evaluation of quality of life.

State of the Art summary:

When studies do report results, mild to moderate changes or no discernible differences are frequent conclusions. There is clearly a gap in the research on high quality, evidence-based outcomes of technology interventions. Demonstrations of feasibility are important for development, but the dissemination of results, particularly on significant impact and clinical health outcomes, are needed to build an evidence-base in the field of gerontechnology. Multiple studies indicate that a technology intervention in dementia care has implications for improving quality of life and shows promise in this area, even if the results do not give strong support for that view. This research study views these broad implications as motivation for the research, to collect and investigate quantitative evidence on quality of life outcomes from using gerontechnology in non-institutional dementia care.

Background discussion and summary:

This chapter shows that the world is aging faster due to an increasing life expectancy and decreasing fertility rates. Current and future generations will most likely continue to experience increasing life spans as technology and medicine continue to advance. There are many factors that influence how long one will live with dementia, such as age, gender, comorbidity, and type of dementia. How people age will be the primary influence on preventative education, age-related health expenditures, and health services. With a growing prevalence of chronic conditions, such as obesity, diabetes, and mild disabilities, the full implications for the general population is yet to be revealed. It is clear, however, that there is a need in global preparation for the projected increase in health and social care needs.

The earlier a dementia diagnosis is obtained, the sooner individuals and families can start to gather information on dementia, access support networks, plan for future living and care, review employment, insurance, and financial options, participate in clinical research trials, benefit from therapeutic interventions and care support services, and health and social care programs can better prepare for the projected need in care. Coyte, Goodwin, and Laporte [99] report that informal care is receding, perhaps due to the declining number of adult children as potential caregivers (recall the 13% decline in populations aged 20 to 39 [23]). With health and social care systems providing different factions of care, it is largely up to the family caregivers to bring the total package of care together for their loved one, serving as the care managers and caregivers. As health and social care systems are changing to adapt to a growing aging population, this should be increasingly based on evidence of best practice for organization, coordination, provision, and assessment of services. Complex technology systems have strong potential to positively influence quality of life. Technologies can perceive the context of the user's environment to aid in tasks at the point of care. To understand the effects of integrating advanced technologies into dementia care, assessment methods and tools need to be developed for this context. Furthermore, it is not enough to match technologies with the level of need, as that would not paint the entire picture of how individuals interact with their home environment nor the technologies implemented in them. Continued work is needed in developing services that extend beyond addressing physical and mental health needs and that are better suited to matching quality of life domains that have been identified by the target patient populations.

Post hoc ergo propter hoc translates from Latin into "after this, therefore because of this", and refers to a logical mistake in identifying a cause simply because it happened first, summarized often as *correlation does not equal causation*. ICT use for specific applications most likely has benefits, but there is little research evidence demonstrating that technology use has a definitive impact on quality of life. When conducting research, the variables, i.e. domains, need to be identified to take a before and after measurement of the same issues, so some reflection on the concept is warranted in order to understand what the variables consist of (development), what the goal of the technology intervention would be (methodology), and interpret what their results say (conclusions). When investigating non-pharmacological and palliative interventions, determining clinical significance is difficult. For example, how many points does caregiver burden need to be reduced on a particular scale in order to achieve clinically significant results? Determining statistically significant differences between test and control groups through experimental models and quantitative outcomes is the most widespread method to evaluate intervention outcomes. However, statistical significance is not synonymous with clinical significance, and the clinical significance of the interventions is obscured when the results from such a heterogeneous group cannot be analyzed cohesively.

The field of gerontechnology is quite young and has yet to build an extensive body of evidence, and there is little definitive knowledge on the relationship between the clinical features of dementia and dementia caregiving, and technology's suitability to intervene on specific symptoms. Clearer conceptual links will support demonstrated effectiveness and assure that indicators of success are useful and meaningful to the individuals that the interventions are aimed towards helping [269]. Using mixed methods research is beneficial when evaluating complex interventions and to provide insight when analyzing multifaceted outcomes. People, including medical and social care professionals, address problems in dementia with both words and numbers to understand and manage the situation, so it is more accessible to describe and evaluate the intervention in a similar manner. Furthermore, the usefulness of the results are supported when they can are described in both numbers (quantitative) and words (qualitative). Caregivers will likely not be as motivated by p-values as they will by whole percentages (i.e. 20 out of 31, or 64,5%, of caregivers who used the technologies had positive effects on their caregiver burden) and success stories they can relate to (i.e. wandering detection in the middle of the night). However, when using mixed methods, the study complexity is increased, which means more efforts are required to fully analyze the results [270]. A standardized ontology to classify the technologies and their outcomes will be beneficial for the multidisciplinary teams that work in this field. Several classification systems were discussed, yet none fulfill the requirements to provide uniform evidence for clinical decision making. It is envisioned that if research and development does not quickly proceed in this area, the technologies will continue to advance much faster than the understanding of the implications. To illustrate this, a brief description of what dementia care could look like in the near future was given, touching on specific devices as well as large, advanced systems of service is given in Paper F. There are important goals that are necessary for technology advancements in dementia care; for one thing, a common system to seamlessly integrate devices and functions into a tailored care plan, and secure network channels are needed to accomplish this. The continued development of technology, particularly in intelligent and ambient technologies that collect and incorporate contextual data to infer situational user requirements, additionally necessitates continued development in how to translate the outcomes of the care interactions to make meaningful interpretations of the data.

This chapter presented the motivation for this research and background information on the topics, showing that demographic changes are creating an urgent need for successful dementia care interventions. The state of the art on high-tech telecare technologies for dementia is presented, including technologies that are currently used and those under development. Linking technologies to recommendations for in-home dementia care provides an overview of how to use technology to supplement best practices in caregiving. Finally, motivating results found in the literature on dementia care interventions are presented. A distinct knowledge gap in the evidence-base of technology intervention outcomes has been identified. The next chapter presents the hypotheses and research questions to be tested.

Papers supporting Chapter 2:

Paper A supports the background by providing a discussion on theories used to understand older adults' experiences of interacting with technology and Paper B discusses the background work on quality of life studies and identifies influential domains of QOL for individuals with dementia. Paper F present a description and discussion of research projects focused on gerontechnology. Paper E offers a discussion on instrumental work in quality of life studies, environment as a mediator for activity, and theoretical motives for the interventions. Paper E also describes a search for quality of life measurement tools. Paper F considers the accelerated co-development of technology and society and the opportunity for technologies to support people with dementia.

Chapter 3. Hypothesis and research questions

Related research has been conducted before; however, there is a lack of cohesive theoretical basis and methodological strategies, which makes understanding the relationship between dementia, quality of life, and gerontechnology evasive and complicated. Generalizing or even comparing results is difficult as it has been a complex and uncertain area of research, and implications are hard to determine. The previous sections have described the increasing need for and use of technology in dementia care despite the lack of evidence to support its effectiveness and efficacy. It seems as though technology-supported care would bring such obvious benefits that people take up its use based on intuition, but this does not explain why results are so difficult to validate for generalization. The rationale for the thesis is grounded in the evidence on the need to understand and further develop technologies that are being used in dementia care (promote the understanding of the use). It is focused on answering the question if technology has a measurable effect on quality of life, and if that effect is positive. Research questions narrow the focus of the research by identifiying the concepts to be investigated, and provide structure to interpret the results. The primary question in the research is to examine if gerontechnology-supported dementia care has different outcomes than usual care, and the supporting questions help to answer this and provide a deeper examination of the outcomes.

This research aims to provide evidence on quality of life outcomes by testing gerontechnology as a dementia care intervention against usual care. The null hypothesis (H_O) is that there will be no differences between the quality of life outcomes from receiving usual care and from using the gerontechnology, meaning that the alternative dementia care (i.e. gerontechnology) is not a significantly different option for the majority of people. The alternative hypothesis (H_1) is that the alternative dementia care (i.e. gerontechnology) yields positive effects when compared to the control group. The ISISEMD-related sub-hypotheses (H_2) are achievement goals that the project set to attain in order to validate the effectiveness of the intervention [271] [272].

Hypothesis Statement: Gerontechnology use will have a positive effect on the quality of life of older adults with mild dementia and on their caregivers when compared to controls

H_O: There is no effect on quality of life; there is no relationship between using gerontechnology in dementia care and quality of life

H_1: Gerontechnology use in dementia care improves quality of life

H_2: ISISEMD-related sub-hypothesis

“Positive” effect is used because maintained physical functioning can delay or defer the need for institutionalization; thus, maintaining quality of life status is viewed as positive. It is challenging to attempt to slow decline, as the individual’s syndrome is unique to their experiences, personality, and environment; there is, effectively, nothing to compare the rate of decline to. For the null hypothesis, rather than stating “negative” effect, the hypothesis is no effect. The rationale is that a negative effect could still indicate that the quality of life had a relationship with the technology use. A negative relationship still gives valuable results to further examine why it was negative and if and how it could be made positive. Additionally, a possible decline in QOL is not an unlikely outcome, especially for participants who have had little to no technology experience, and who may become initially distressed by having a care technology system installed in their home. The research questions from the ISISEMD project help to narrow the indicators for testing the hypotheses. The research questions define what the research will be investigating to determine the significance of the outcomes:

1. Will using gerontechnology have positive effects on physical and independent functioning?
2. Will using gerontechnology have positive effects on the quality of life of the individuals with dementia
3. Will using gerontechnology have positive effects on the quality of life of the caregivers?
4. Will using gerontechnology have positive effects on caregiver burden?
5. Will using gerontechnology have positive effects on safety in the home?
6. Will people be satisfied with the intervention system?
7. Will people want to use services like these in dementia care?
8. Will people be willing to pay for services like the ones offered?

Chapter 4. Methods

Development, implementation, and evaluation of the telecare intervention

This chapter describes the methodology to test the priori hypothesis that using gerontechnology in dementia care would improve quality of life in participants when compared to a control group. The previous research reveals that the capacity to have positive effects on overall quality of life may be measured by assessing specific elements thought to indicate quality of life (i.e. physical functioning, functional independence, quality of life, caregiver burden). To this end, this research study compares multiple indicators of quality of life, under the assumption that these individual elements will have an effect on overall quality of life, and by viewing quality of life from several influential angles that will provide a more holistic view of the construct. A network of adaptable technologies were installed in the homes of individuals as part of their dementia care during a 15 month testing period in the four European locations of North Ireland, Finland, Greece, and Denmark. This intervention group was compared to n=26 control participants in 3 of the 4 regions[23]. All older adults had a designated caregiver and were living in their own homes and all participants gave informed consent. The ISISEMD clinical intervention trial tested 80% power against a Type I error with the null hypothesis that there would be no significant difference in outcomes between two types of care. All intervention group participants discussed the telecare plan with project partners before the installations in order to tailor the services and provide the most support. The expected benefits would be more maintenance or even improvement in the key areas when compared to a control group of usual care. The harms that are addressed as primary concerns are increased frustration/stress due to adapting to the new technology and issues related to data security. To acquire information on the user requirements outside of academic investigations, a triangulation of methods consisted of standardized tools, semi-structured interviews, and observations by professionals. In this way, representative end users could introduce ideas, experiences, practical knowledge, and preferences. The basic requirements help to determine which services will be beneficial, have the most impact, be considered acceptable, etc. Since these derived requirements were preliminary, they were continually revised and assessed during the rest of the project, particularly during the integration and implementation phases when the scenarios were no longer models but based on actual individuals. The telecare intervention was tailored, multi-component, and long-term, all of which have been recommended for effective dementia care interventions [273].

The outcomes were measured by quantitative data gathered from the ICT system and through observations, interviews, and questionnaires to the end users. The ISISEMD project consulted with relevant national experts in the countries on criteria and assessment tools. Determining statistically significant differences between test and control groups is the most widespread method to evaluate clinical outcomes. However, statistical significance is not synonymous with clinical significance. Mixed methods are used to evaluate the multifaceted intervention. It is often difficult to determine the clinical significance of non-pharmacological and palliative interventions. For example, what is the minimum detectable change in quality of life needed (or, in which domains, or in which assessment tool) in order for the outcome to be clinically significant? Well-defined clinical relationships help determine the appropriateness of the intervention's objectives, yet the clinical features of dementia and dementia caregiving are not well understood. When describing a complex intervention that is intended to enrich people's lives, it can be more effective to communicate the outcomes in a way that puts meaning on the usefulness of the intervention, both in numbers (quantitative) and words (qualitative).

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[23] The end user region of Denmark could not recruit enough participants to effectively be randomized into control and test groups; as a result, there was not a control group included from this region.

Papers included in Chapter 4:

Paper B supports this chapter by discussing a prototype for an electronic quality of life assessment for use in dementia care.

Paper B: Carrie Beth Peterson, Neeli Rashmi Prasad, and Ramjee Prasad. “Framework for Dementia Quality of Life Assessment with Assistive Technology,” Proceedings of the International Association of Science and Technology for Development (IASTED 2010) in Innsbruck, Austria, Biomedical Engineering Volume 1. ACTA Press 2010. ISBN: I: 978-0-88986-825-0/II: 978-0-88986-827-4. 6 pages.

Paper D defines the ISISEMD development, implementation, and evaluation methods as well as an additional explanation of the services.

Paper D: Anelia Mitseva, Carrie Beth Peterson, Christina Karamberi, Lamprini Ch. Oikonomou, Athanasois Mpallis, Charalampos Giannakakos, and George E Dafoulas. “Gerontechnology: Providing a helping hand when caring for cognitively impaired older adults – intermediate results on the satisfaction and acceptance of informal caregivers from a controlled study.” *Current Gerontology and Geriatrics Research*, Hindawi Publishing, Article ID 401705, 2012. DOI: 10.1155/2012/401705. 19 pages.

Paper E reports a literature search for dementia-specific quality of life assessment tools that could be used to evaluate telecare impact. This paper also considers revisions to the proposed electronic QOL assessment prototype.

Paper E: Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. “Assessing assistive technology outcomes with dementia.” *Gerontechnology 11(2)*, p. 259. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.414.740. 10 pages.

Paper F presents a cutting-edge description of gerontechnology use, evaluation, and continued development that is accelerated through advancements in technology, indicating a need for electronic QOL assessment methods.

Paper F: Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. “The future of assistive technologies for dementia.” *Gerontechnology 11(2)*, p. 195. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.427.742. 7 pages. Awarded “Best Paper” at the International Society for Gerontechnology conference, 2012.

Papers G and H describes the methods used in the study.

Paper G: Carrie Beth Peterson, Lars Bo Larsen, Poul Svante Eriksen, and Ole K Hejlesen. “Zarit burden interview shows decrease in caregiver burden with technology intervention in European dementia study.” Submitted for publication to the *British Medical Journal*, 2014.

Paper H: Carrie Beth Peterson. “Results from a clinical trial on gerontechnology in dementia care and caregiver quality of life outcomes.” Technical report, 8 pages, 2013.

4.1 Recruitment and retention of participants

In this study, the focus is on older adults with milder forms of dementia. The study required participants who will adapt to using technology in the home and to the telecare services, as well as have the ability to give their assessment. The goal of the inclusion and exclusion criteria for participation in the clinical trial was to acquire a group of end users who have the experiential knowledge of living with and caring for dementia and are able to give their evaluation[24]. As the MMSE is the most widely used cognitive assessment in dementia evaluations, the cut-off for exclusion was based on mild to moderate range of dementia, corresponding to a score between 10 and 25. However, there are known fallacies with the MMSE as diagnostic criteria for dementia, and there are wide variations among individuals with dementia. Depending on educational level, age, and other personal history, it is feasible that a person can present symptoms of dementia yet show a score of no impairment. As discussed earlier, not every person who meets the criteria of symptoms will have a dementia diagnosis. The inclusion criterion is intended to exclude participants with severe dementia, who may not be able to provide their evaluation of the intervention, so participants scoring within the normal range of cognition (≤26) are included in this study if presenting symptoms of cognitive impairment or dementia. The project did not focus on diagnosis or differentiation of dementias, but aimed to exclude participants who had dementia secondary to head trauma, psychological conditions that were similar to dementia, and misuse alcohol or medications; furthermore, those who have had more than 3 acute hospitalizations in the past year are at an increased risk for a confounding delirium or reversible cognitive impairment would also be excluded. This was to avoid possible variations of cognitive impairment that did not have the same etiology and needs as the intended population sample. In the same light, those with known Frontotemporal dementia were excluded as their syndrome will have different symptoms and they are prone to different mood and behavioral changes. As one of the goals of the gerontechnology intervention was to improve socialization and independence, individuals who are bedbound are believed to have needs and user requirements outside of the scope of the project.

Caregivers were required to be consenting adults (over age 18, no dementia themselves), have a history of caregiving, and were excluded if they were undergoing active treatment for cancer. Caregivers needed to have a history of caregiving so the role and responsibilities would not be a new adjustment in their lives (which could indicate an initial increased burden), and so they could have a better perception for personalizing the dementia care. Active treatment for cancer is a significant experience which can leave the person physically and mentally depleted, and could present spurious outcomes in caregiving. There also needed to be some stability of the home environment in order to test an intervention in that context, so participants were excluded if there were plans to move during the duration of the trial. An ideal description of the participants is given in Table 4, and includes community-dwelling older adults with dementia and their adult caregivers who are experienced and able enough to give an assessment of their quality of life.

Table 4 Inclusion and Exclusion criteria for the ISISEMD pilot trial [274] [275]

Participant group	Inclusion criteria	Exclusion criteria
Individuals with dementia	≥ 60 years of age Mild to moderate symptoms of dementia (measured by MMSE >9) [276] Live in their own home (alone or cohabitating) Have an informal caregiver Can give consent	Dementia secondary to head trauma Frontotemporal dementia Dementia that is reversible Psychological condition similar to dementia or long-term psychological conditions Misuse alcohol or medication Bedbound (20 hours a day for 4 of 7 days) Malignant illness Under active treatment for cancer or other terminal diagnosis >3 acute hospitalizations that were not dementia-related in the past year Planning institutionalization in the next 6 months
Informal Caregivers	Over the age of 18 Live with or near the participant with dementia Currently involved in care for ≥6 months Have no plans to move during the duration of the intervention trial	Under active treatment for cancer Have dementia themselves

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[24] These main inclusion/exclusion criteria have been consulted with Bodil Gramkow, chief physician at Department of Psychological and Gerontology in Brønderslev, Denmark and Kasper Jørgensen from the National Research Center for Dementia for Dementia in Denmark.

The assessments used in this PhD study were administered before the trial began and again after the 15 month trial period was over. The assessment tools used have been designed and recommended for research in dementia care and quality of life outcomes (i.e. physical functioning and independence, quality of life, and caregiver burden), and are administered in the local language. The results of these assessments will be compared, based on significant change from the baseline assessment and on significant differences between the control and intervention groups' outcomes. The control group will have care as usual (both formal and informal, and allowed to change as needed). Before participants could be recruited, all regions obtained approval from Data Protection Authorities for the collecting, treating, and storing of personal information and Ethical Committee approval where necessary [273] [277]. The national and international regulations on the privacy and ethical treatment of participants and data were respected, and this is further described in Paper D. The ethical applications began in September, 2009 and all were approved by April, 2010. For detailed information on the European and National ethical guidelines and approval for the ISISEMD project, see the public report "Specification of tests and test groups, update," [274]. The trial protocols included guidelines on oral and written information for the participants, lists of equipment, informed consent forms, etc; however, no registration is required for Phase I clinical trials testing medical or therapeutic devices.

The trial is quasi-experimental (non-randomized) with repeated measures, and the results are gathered through mixed methods. Additionally, the research is exploratory, since so little is known on technology interactions in dementia care and on the outcomes of such interactions. A non-inferiority framework is used in order to demonstrate that the gerontechnology intervention provides at least the same benefits to the dyad as usual care.

Health care systems did not have access to people in the early stages of dementia as they usually do not seek out formal support services until the dementia is advanced enough to cause problems. Therefore, it was difficult to find participants in the earliest stages of dementia. Particularly when working with milder forms of dementia, symptoms can change rapidly and some participants may not be suitable for the entire duration of the trial, so it is expected that a certain number of participants will withdraw from clinical trials. The participants from the four countries (Denmark, Finland, Greece, and North Ireland) were recruited using multiple channels, consisting of general practitioners and nurse practitioners, dementia clinics, and regional organizations working with dementia populations. The majority of referrals were contacted via memory clinics or by the home-care personnel in the municipalities. It was not uncommon that the medical providers in the regions were unfamiliar with the telecare technology, and did not understand the scope of the project, which made it difficult for them to refer appropriate patients. Unfortunately, many of the referred individuals did not meet the criteria to participant, often due to more advanced dementia. Television and radio channels were also used to announce the pilot study and to attract interested participants, and regional partners set up demonstration rooms for live or televised demonstrations of the services. Here, the participants could see and experience the telecare system prior to joining the clinical trial, the formal caregiving staff could interact with the system for technical feedback and training, the technical partners could test services and updates, and other members of the community could learn more about the telecare system through demonstrations.

An average QOL-AD score is reported as 39,5, with a Standard Deviation of 5,3 [178]. ISISEMD aimed to measure a 6% increase in QOL-AD score, with 95% Confidence and 80% power, so n=37 participants per group were needed for validation [274] [275], and ISISEMD aimed to recruit 40 in each group (10 per group in four sites) to accommodate for attrition. N=71 older adults with probable mild to moderate dementia and their caregivers (i.e. dyads) were assessed for appropriateness to participate in the project. Of these, n=63 were suitable for the project; however, n=6 out of 45 (13,3%) withdrew from the intervention group and n=2 out of 26 (7,7%) withdrew from the control group before the final evaluation. The most common reasons for withdrawing from the project were due to a deterioration in health or family life (i.e. overall health status declined, hospitalization, stroke, death), internet connectivity issues necessitating removal from the intervention group, and one dyad withdrew in Denmark due to an inconvenient number of technical issues and the belief that the person with dementia was well enough to manage without additional care [275]. After withdrawals, n=55 dyads (87,3% of those appropriate) completed the length of the trial. The initial methodology was to randomize participants in each of the regions; however, due to recruiting difficulties, ISISEMD amended the methodology to prioritize accruing participants in the intervention group. In the Denmark region, the consortium decided that all 10 would be assigned to the intervention group in that region (n=4 of whom later withdrew). Additionally, the exclusion criteria specified dementia secondary to head trauma and being bedbound; however, one participant was both bedbound (in a wheelchair) and suffered cognitive impairment secondary to a head trauma (due to a fishing industry accident years ago). This dyad was discussed, and it was decided they could remain in the trial. Furthermore, some of the participants lived in mountainous areas with poor connectivity, and they were reallocated to the control group as it was not technically feasible to offer the services.

4.2 Service development and implementation

Telecare services all will consist of a network layer, platform layer, and user layer, but the services often overlap and there are divergent classifications of technologies and services. The technical capabilities of the gerontechnology system allowed scalable services and supported user requirements being met in terms of functionality, privacy and security, speed, capacity, accuracy, and standards. The technical partners determined which equipment would best match user needs and designed the scalable services. The technical partners ensured that the user requirements were met by technical capabilities in the working version and fall back solutions, and were maintained throughout the trial. The care professionals in the regions ensured that the services were appropriate for the end users. All project partners assisted in testing, debugging, and adapting the services. Table 5 presents examples of the ISISEMD telecare services and technologies in the gerontechnology matrix.

Table 5 ISISEMD services and technologies in the gerontechnology matrix

Class of technology	**Area of activity**				
	Health and self-esteem	*Housing and daily living*	*Mobility and transport*	*Communication and governance*	*Work and leisure*
Enhancement and satisfaction	Access to telecare services	Lifestyle pattern monitoring	GPS device with mobile communication	Carebox contact button	Digital pictures in Memory Lane service
Prevention and engagement	Reminders for meals	Motion sensors for wander alert	Bed sensor	Carebox contact button	Brain games on Carebox
Compensation and assistance	Reminders for medication	Kitchen equipment control	GPS device with mobile communication	Reminders for date and time	Reminders for activities
Care support and organization	Patient records in the telecare system	Overview of the home via the portal	Better coordination of visits by checking GPS	Reminders entered by caregivers	Coordination of care and support for caregivers

The services were designed to be more passive for the adult with dementia. Their main interaction with the system would be through the Touchscreen computer, and a graphical user interface (GUI) needed to be developed particularly for them. Caregivers are also often aging adults, so their GUI is designed to be appropriate for their needs and abilities as well. A group of experts working in the field of Human-Computer Interaction (HCI) focused specifically on GUIs that are appropriate for all potential users and set parameters for design that accommodate aging adults' needs [278] [279]. In this research, these design parameters were used when creating the GUI for the person with dementia, and in the information and training materials. The design parameters for functional changes associated with aging include:

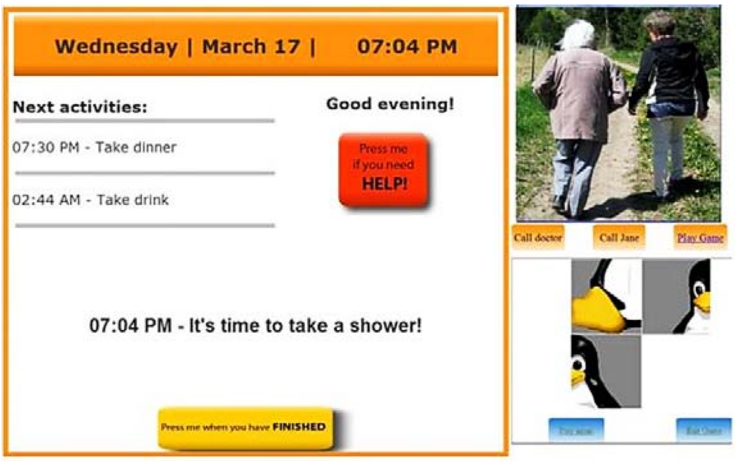
- **Vision** – declining sharpness, contrast and glare sensitivity, visual color discrimination, etc.
- **Psychomotor abilities** – reduced reaction time, finger dexterity, and arm-hand steadiness
- **Attention** – declining ability to concentrate and manage multiple tasks simultaneously
- **Memory** – reduced working memory (ability to retain information)
- **Learning** – speed of information processing is slower
- **Intelligence** – fluid intelligence (i.e. ability to think and reason, speed at which information is analyzed) and crystallized intelligence (i.e. accumulation of information and problem solving) are reduced
- **Expertise** – older adults are typically not proficient in the latest technologies or their processes

Applying activity theory to HCI provides a framework to understand the co-creation between human activities and technology that promote long-term well-being. In this way, the theory provides a perspective on the user's situation and focuses on the interaction, with the emphasis on the interaction in the transient context. There are care and living requirements for the person and the place, and notifications and alarms are dependent on the user and the device. This helps to make the important distinction between which technologies are *usable* and which are *useful*. For example, a door opening at night may be normal and acceptable for one user but signify a serious threat for another. In the first case, the movement would be recorded in the system but would not require the immediate attention of the caregiver; in the second situation, the movement is recorded in the system and an alarm is generated to the caregiver. These requirements may change during the course of the trial and are expected to change over the lifetime as the syndrome advances. The ISISEMD Carebox GUI is designed for simplicity and minimal interaction. In the interface for the adult with dementia, there are no pop-up windows, dialog boxes, or menus to cause unnecessary distractions. The GUI is displayed on the HP

TouchSmart Desktop PC (models are either with a 20” or 23” screen), and the components of the GUI are in fixed positions based on 4 areas of use, presented in Figure 9.

Figure 9 Graphical User Interface components and their fixed position [275]

The top left side of the screen displays information on the structure of the day (date, day, time, upcoming activities).	The top right side of the screen displays the pictures in the Memory Lane service.
The bottom left side presents messages and reminders. This is enhanced through sound and the options for audio messages and confirmation button (for when activities have been performed).	The bottom right side presents the video phone and Brain Games services.



Wednesday | March 17 | 07:04 PM

Next activities:

Good evening!

07:30 PM - Take dinner

02:44 AM - Take drink

07:04 PM - It's time to take a shower!

The integrated prototype consists of an infrastructure including diverse Hardware (HW) devices (i.e. fixed and mobile devices) and Software (SW) components, which required adaptations in order to realize the desired infrastructure. There were some integration issues with physical and virtual allocation on the network (i.e. debugging, faulty equipment, temperature sensing when cooking, connectivity), and all were resolved. The servers were installed in a web farm at Alcatel-Lucent Multimedia Communication Center in Milano, Italy [280]. The web farm offers Internet and WiFi connectivity, web hosting, data storage, a mail server, and authentication and encryption of data. The physical architecture is comprised of physical servers and virtual machines, based on the servers installed in the Demilitarized Zone (DMZ) Network at Alcatel. The DMZ Network adds additional security against external attacks. A virtual appliance hosts the SW stack of the Ecosystem (i.e. operating system and networking, remote access, security, etc.). The virtual appliance has minimal overhead and makes it easier to compartmentalize and administrate the various technical domains involved (i.e. changing underlying HW components, modify operating systems, reduce SW interference, etc.). The ISISEMD system architecture can be seen in Appendix 6.

The technical verification, replication, and testing ensures that the technical components and services will run according to the defined requirements. The testing has been carried out in three sub-areas of integration, functions, and Carebox. The integration testing ensures the basic integration of sub-systems, their communication, and operation through the portal. These tests were conducted while the ISISEMD partners were in a conference call so that appropriate partners could provide input. Errors are corrected immediately and the test is run again until all integration was tested on the servers and portal. The integration test shows that the different sub-systems are successfully integrated and have functional communication. The functional testing focuses on the actual use of the system and actual functionality of the services. After passing the integration tests, the ISISEMD portal is accessed and tested to verify that the system behaves as expected. Any system bugs are corrected and the function is tested again, this is repeated until the platform passes all functional testing. The Carebox is tested to confirm that the home PC performs appropriately for the end users. The Carebox and GUI are tested by simulating activities that the caregivers or individuals with dementia would carry out, and includes verifying that GUI items were displayed properly, services can effectively be modified (i.e. reminders, scheduling events, pictures can be uploaded and displayed), and notifications via SMS and email are successfully delivered. There were minor issues with the pressure needed to activate the touchscreen (i.e. contact button), and this is specifically addressed in the training where participants with dementia would test the button to get used to the amount of pressure (this also helps to reduce the inexperienced user's feelings of apprehension about breaking or damaging the system). The Carebox not only provides the human-machine interface, it performs as the domotics controller (connects the home automation components) and serves as a communication device. The home automation server and the GUI are tested separately, and then together to verify the Carebox functionality. This testing guarantees that messages and information are received and appropriate action follows (i.e. alerts or alarms displayed through text, audio, SMS, or email). Once the services and components have been tested, the services are set up (i.e. loading the interface, modifying services and parameters, adding phone numbers and email addresses, etc.), and ready to be implemented in the homes.

Due to the varying individual requirements and to the progressive nature of dementia, the services are grouped in three bundles of increasing care, presented in Table 6. Some of the basic services (lower level of care) include sensors for temperature, and fire and flood sensors, while the more advanced services (higher level of care) include meal and appointment reminders, medication management, indoor/outdoor activity sensing, and lifestyle pattern detection. Paper D provides a further description of the services. The technology skills among the end users can also vary, which is why in-person training as well as user manuals, and online information are used [274]. For the adults with dementia, the system requires as little interaction for them as possible. The participants have the freedom to choose which services would best serve their living situation and care preferences.

Table 6 Technology-enabled services offered through the ISISEMD project [281]

Service group	Service summary
Basic	Home safety • Kitchen equipment control (stove and oven) • Smoke, fire, and flood detectors • Door monitor (for wandering)
Basic	Reminders • Daily schedule (reinforce structure of the day) • Date and time (orientation) • Medication
Basic	Brain games • Exercise cognitive functions
Medium	Motion detection • Bed sensor
Medium	Away from home • Register when leaving and returning home • Notification to caregivers if away from home longer than pre-defined
Medium	Internet telephony • Contact through Carebox touchscreen contact button
Medium	Memory lane • Enjoyment of activities • Picture files displayed on the Carebox
High	Positioning • GPS when outdoors • Panic button • Mobile telephony
High	Lifestyle pattern • Detect deviation from normal behavior

Different levels of user support are used. The first level is provided by the trained professional caregivers in the regions (i.e. super-users), who train the participants and receive the subsequent requests for help. If the formal caregiver cannot resolve the problem, they create a detailed request ticket for the technical partners. The ticketing system helps to define user support roles and responsibilities, service level agreements, allows for tracking the progress in resolving the issues, and in the dissemination of the problem-solving. The second level of user support is assisted by the IT Infrastructure Library and is service-focused. The web-based portal contains a Help Desk area with forms that the participants (i.e. formal and informal caregivers) can use to classify and request support, and the backend of the portal processes the requests (i.e. assigned, replied, archived, etc.). The Help Desk also has a hot line to facilitate communication between the caregivers and the service support partners (both technical and care-related).

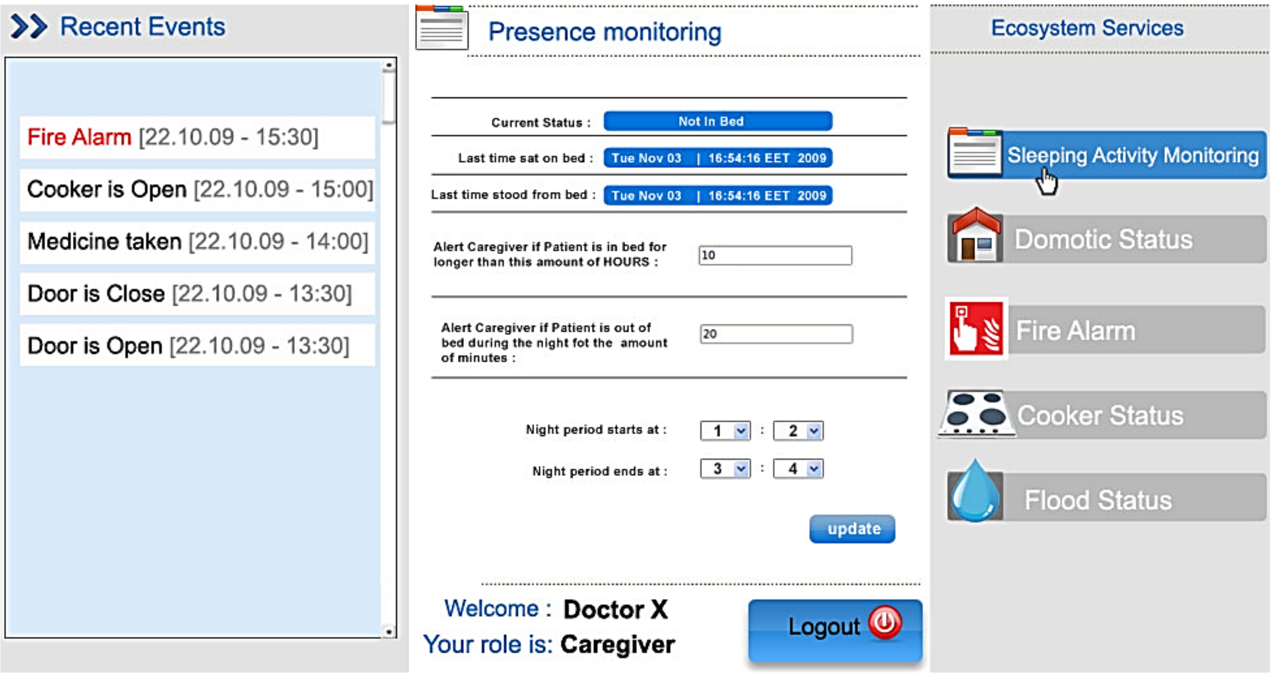
The services need to be understandable and adjustable for the end users, particularly the caregivers. For example, the system would make an alert if the windows are left open past a certain hour in the night, and this could be adjusted if it was summer and acceptable to keep the windows open. Similarly, the event notifications could be adjusted for shorter periods if, for example, there is a family event and the caregivers wished to turn off the "door open" notification as there will be many people entering and leaving the house that day. This requires training to encourage a deeper understanding of how the gerontechnology system works, so the caregivers can accurately interpret the information recorded in the system as well as make adjustments that work best for the individual. During the installation phase, formal caregivers and technical partners carried out the majority of the face-to-face training, which includes going over the printed material and their instructional pictures on how to set up, use, and manage the services. The regions had variations in the time for installations, largely due to the number of wires, sensors, and technical issues. Installations took from 1 hour to 1 day, with the average being a few hours per home. It was found effective to first explain and demonstrate the service, and then ask the participants to try it out. The amount of time spent on training the end users varies (several hours per home), and there are differing levels of expertise with technology. All users received manuals with instructions and picture guides tailored to their user level and their technical level As with the user interfaces and service functions, the user manuals are in the local language for the individuals with dementia, the informal caregivers, and for the formal caregivers. Training on the personalization of settings for the reminders and alarms was specifically addressed. The portal had a user manual and Frequently Asked Questions (FAQ) file that was tailored to be appropriate for the type of end user (informal or formal caregivers). After the installation of the telecare system in the home, the participants could request further or ad hoc training and had access to supplementary information. The regional experiences with installations, training, and user support are summarized in Table 7.

Table 7 User support and installations in the telecare pilot [272] [281]

Region	Installation	Support
Lappeenranta, Finland	From 1 hour to 1 day, depending on type of installation (number of wires, sensors, technical issues).	Training took approximately one hour per user, specifically, the reminders and alarms services were addressed. Caregivers were trained in using the portal and to modify the settings. Users were supported through ad hoc training. On site visits for subsequent problems proved effective in enhancing the system.
Frederikshavn, Denmark	Installations were more time consuming than education. The system was found to be complex to install.	Educating the users took up to 4 hours per family. It was effective to train the caregiver and person with dementia together, and it promoted unity in the dyad. However, to have the dyad together required training outside of business hours. It was important to teach the caregivers about the details in personalizing the services, so they feel confident in using the system.
Trikala, Greece	Installation varied from 2 to 5 hours, depending on type of installation (number of sensors).	Professional caregivers worked in the same place as the technical partners and were easy to train. This seemed to positively influence smoother running of the pilot. More advanced training and education materials were given to more advanced users, specifically, on personalizing the services.
Belfast, North Ireland	Installations varied. Problems with Internet coverage increased the time spent on installations.	Face-to-face training was given in a demo room and at the home, during installations. The participants required more support than was anticipated.
Summary of recommendations:	Technical and regional partners are recommended to have established plans for the installations so the process is more consistent.	Make "how-to" video clips to enhance caregiver training and education. It is a challenge for caregivers (both professional and informal) to learn how to use the system, and what it can and cannot do. Formal caregivers were further trained by project technical members, and additional training was made available.

Through the telecare portal, caregivers can log in to see the status of the home, recent activities, and adjust the parameters for an individual's allowed activities. Alerts are generated when the system has detected an activity (or lack of), but it does not require immediate or emergency-level action (e.g. a yellow light). For instance, an individual with dementia typically gets out of bed to go into the bathroom 3-5 times a night; an alert would be generated to the designated caregiver if this person goes beyond those parameters, e.g. goes into the bathroom more than 5 times in one night or does not go to the bathroom at all in a night. In general, the alerts mean that the system detected activity outside the pre-defined parameters and encourages a closer look at the issue or situation. Alarms are generated when the system has detected activity (or lack of activity) that requires immediate or emergency-level action (e.g. a red light). Examples of alarms generated would be if the fire detector is activated. The alarms are connected with the central unit in the home (the Carebox, as it was called in this project), which sends out the messages about the type of alarm. The Carebox serves both as a domotics controller in the home and as a communication device. Figure 10 presents an example of the formal caregiver's overview of the home telecare system.

Figure 10 Example of the ISISEMD formal caregiver's overview of the home status for a patient



Recent Events

Fire Alarm [22.10.09 - 15:30]
Cooker is Open [22.10.09 - 15:00]
Medicine taken [22.10.09 - 14:00]
Door is Close [22.10.09 - 13:30]
Door is Open [22.10.09 - 13:30]

Presence monitoring

Current Status : Not In Bed
Last time sat on bed : Tue Nov 03 | 16:54:16 EET 2009
Last time stood from bed : Tue Nov 03 | 16:54:16 EET 2009
Alert Caregiver if Patient is in bed for longer than this amount of HOURS : 10
Alert Caregiver if Patient is out of bed during the night fot the amount of minutes : 20
Night period starts at : 1 : 2
Night period ends at : 3 : 4

Welcome : Doctor X
Your role is: Caregiver

GPS tracking with mobile phone communication for outdoor positioning

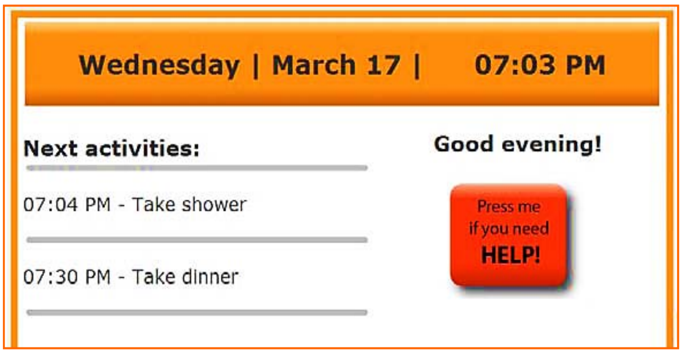
Particularly in dementia care, tracking technologies have been used in social services and locating systems. For the individuals, the use of this technology can increase (a sense of) independence by knowing that they can push a button to call for help or to be found if they become disoriented. The device shown in Figure 11 provides localization through GPS (Geographical Positioning System) and GSM (Global System for Mobile communication), and functions as a mobile communication device through SMS (Short Message Service) or GPRS (General Packet Radio Service). It has only one distinct, red button that supports 2-way voice communication (initiates a mobile call to the designated caregivers and to receive an incoming call from the caregivers) and contains an accelerometer to detect movement and falls. The model used in the project is the personal Lommy (www.flextrack.dk). The Lommy costs around €350 and is roughly the size of a deck of cards, is water resistant and dust protected, and takes under 5 hours to recharge after 40 hours of active use. This device is used for locating the person when they are outside of the home and for communication. For example, in Denmark, it is common to take walks outdoors, and the formal caregiving staff would first check the location of their patients to make sure they were in the house before driving out for a home visit. Alternatively, some older adults resumed outdoor walks once they had the GPS device because they were less afraid of becoming lost and no one finding them.

Figure 11 End user with the GPS-enabled device

Daily schedule and reminders through the touchscreen interface

With dementia, there is a characteristic difficulty in creating and keeping the structure of the day, and this is often one of the first symptoms noticed in early dementia. The electronic calendar, shown in Figure 12, provided orientation as to the time of day, the date, month, and year, as well as prompted the structure of the day through reminders, i.e. to take medication, prepare or eat a meal, or scheduled visitors to the home. It was intended that there should be minimal interaction from the end user, unless they expressed a desire for more interaction, e.g. to add reminders to the calendar themselves.

Figure 12 Example of the structure of the day and contact button on the touchscreen interface [282]



Wednesday | March 17 | 07:03 PM

Next activities:

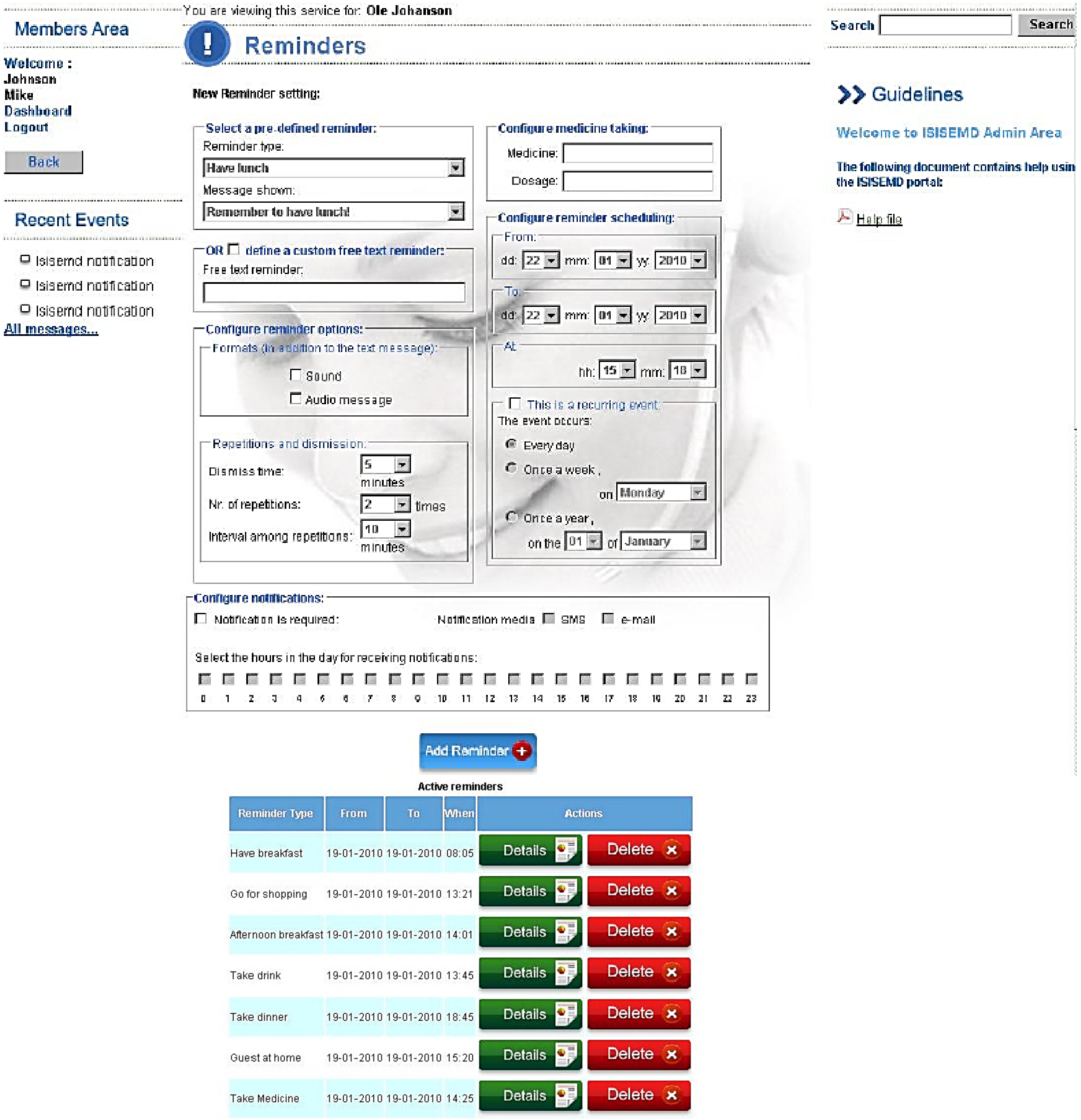
07:04 PM - Take shower

07:30 PM - Take dinner

Good evening!

The caregivers could add, remove, or change calendar events, shown in Figure 13. The formal caregiving staff could add to the schedule if they were going to make a house call, and some of the caregivers also used the system for personalized reminders, such as to enjoy a glass of wine with dinner [275]. In addition to the calendar providing reminders and prompts, it also has the capability to display alerts. For example, if the stove has been left on for too long (based on the user-defined parameters), an alert would read across the screen, first promoting the aging adult's independence by giving them the opportunity to resolve the issue. The alert is also sent via SMS or email to the caregiver. Depending on the action taken, the caregiver could also receive a message that the issue had been resolved or was now at alarm status if the issue was not resolved during a predetermined and individual user-defined amount of time.

Figure 13 The caregivers can personalize reminders to be displayed on the ISISEMD Carebox



You are viewing this service for: **Ole Johanson**

Members Area

Welcome :
Johnson
Mike
Dashboard
Logout

Recent Events

- Isisemd notification
- Isisemd notification
- Isisemd notification

All messages...

Reminders

New Reminder setting:

Select a pre-defined reminder:
Reminder type: Have lunch
Message shown: Remember to have lunch!

OR ☐ **define a custom free text reminder:**
Free text reminder:

Configure reminder options:
Formats (in addition to the text message):
☐ Sound
☐ Audio message

Repetitions and dismission:
Dismiss time: 5 minutes
Nr. of repetitions: 2 times
Interval among repetitions: 10 minutes

Configure medicine taking:
Medicine:
Dosage:

Configure reminder scheduling:
From: dd: 22 mm: 01 yy: 2010
To: dd: 22 mm: 01 yy: 2010
At: hh: 15 mm: 18

☐ This is a recuring event:
The event occurs:
● Every day
○ Once a week , on Monday
○ Once a year , on the 01 of January

Configure notifications:
☐ Notification is required: Notification media ☐ SMS ☐ e-mail

Select the hours in the day for receiving notifications:

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23

Active reminders

Reminder Type	From	To	When	Actions
Have breakfast	19-01-2010	19-01-2010	08:05	Details Delete
Go for shopping	19-01-2010	19-01-2010	13:21	Details Delete
Afternoon breakfast	19-01-2010	19-01-2010	14:01	Details Delete
Take drink	19-01-2010	19-01-2010	13:45	Details Delete
Take dinner	19-01-2010	19-01-2010	18:45	Details Delete
Guest at home	19-01-2010	19-01-2010	15:20	Details Delete
Take Medicine	19-01-2010	19-01-2010	14:25	Details Delete

Guidelines

Welcome to ISISEMD Admin Area

The following document contains help usin
the ISISEMD portal:

Help file

Communication with family and caregivers through the touchscreen interface

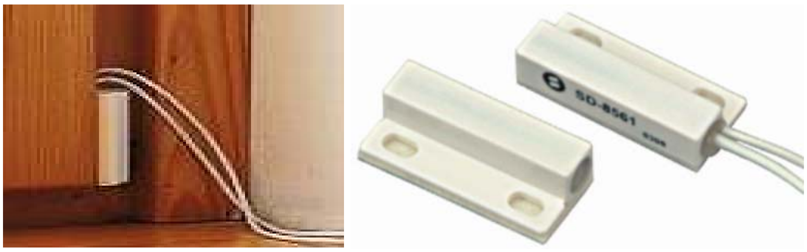
Aside from the contact allowed by the GPS device, the older adult could contact their family or caregivers in other ways. On the older adult's touchscreen computer interface, there was a call button that would call to landline or mobile phones, shown in Figure 14. Although the initial design of this service was intended to be for emergency contact, at least one older adult had lost their ability to use the home telephone and would use the touch-screen phone to make regular calls to their caregivers. In this case, it was noted as a normal parameter of use and no longer raised alarms for the caregivers. This exemplifies the innovative adaptation to the environment by people with dementia.

Figure 14 Activating the contact button on the Carebox touchscreen interface

Access control to the home

Many aging adults enjoy the independence of going to shop, taking walks, or attending local activities. For this service, if the person with dementia has not returned to the home after a pre-defined time, an alarm is raised. This service is also adaptable, so that in the case that the person is no longer safe to leave the house alone, the alarm is immediately generated to caregivers when the front door is opened. Figure 15 gives an example of the door sensor, which uses electro-magnetic switching to register door and window opening and closing. In the Nordic countries (Denmark and Finland), it can become very cold in the winter and losing a disoriented loved one outdoors is a fear that causes worry and stress among caregivers. The model used in ISISEMD project is the Sunwave SD-8561W and costs around €2 each (www.sunwave-america.com).

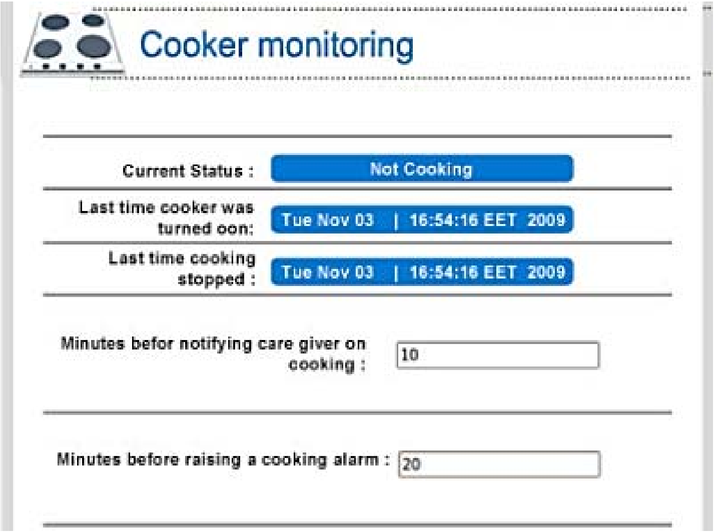
Figure 15 Access control sensor used in the project



Kitchen equipment control

Initially, the kitchen monitoring service was to provide control through the parameters of time and temperature, but during the installation phase, it was realized that many people like to open their kitchen windows when cooking and this skews the temperature sensors and causes false-negatives. To accommodate the end users, this service controls the cooking safety through time-based parameters and actuators will disconnect the electricity when the cooking time is exceeded. Each person has a pre-defined amount of time to carry out their cooking activity (i.e. if the end user only boils water for coffee or tea, the amount of time is shorter than for the end user who prepares meals), shown in Figure 16.

Figure 16 Example of caregiver portal overview of cooking activity



Cooker monitoring

Current Status : Not Cooking

Last time cooker was turned oon: Tue Nov 03 | 16:54:16 EET 2009

Last time cooking stopped : Tue Nov 03 | 16:54:16 EET 2009

Minutes befor notifying care giver on cooking : 10

Minutes before raising a cooking alarm : 20

Smoke and fire detectors are also used, the Cooper M12 model costs around €15 (www.coopersecurity.co.uk). This device uses dual in-line switching and alerts for smoke and fire through 4 programmable detection capabilities: optical (detecting light scattering due to smoke), optical and the rate of the rise in temperature, rate of rise in temperature (proportional to the external temperature), and fixed temperature (detects a high temperature). In-home motion detection was integrated through the Bosch Blue Line P1 (www.bosch.co.uk), shown in Figure 17. The device costs €15 and works as a Passive-Infrared (PIR) detector, using a Fresnel optical lens and First Step Processing (FSP), which delivers a nearly instant response to human movement and reduces false alarms due to air circulation, insects, and pets in the home. The Cooper Safety 1450 detects flooding in the homes and the changeover relay outputs to the domotics controller when an event is sensed (www.coopercsa.it). The device, shown in Figure 18, costs €20 and detects moisture and flooding through the resistance between the 4 gold-plated feet and the internal coils. To monitor nighttime and restful activities of the person with dementia, the RECORA bed occupancy sensor is used in the homes and costs around €75 (www.recoraco.thomasnet.com), shown in Figure 19. The sensor (mat or strip) is about ½” thick stainless steel (some models have gold plated stainless steel for higher conductivity) and works on smooth surfaces (e.g. chairs, mattress, wheelchairs). The low voltage contacts are normally open and will close when the presence of more than 5 lbs. of weight is detected. The sensor is connected to the domotics system and notifications are raised if, for example, the individual has not returned to bed in the middle of the night after a predetermined time.

Figure 17 Passive-Infrared motion sensor

Figure 18 Moisture and flood sensor [282]

Figure 19 Bed occupancy sensor [282]

The ASUS PL-X31, shown in Figure 20, is the Ethernet Powerline Network adapter bridge in the homes and costs around €50 (www.asus.com). It has an AC power port (AC 100-240/50-60Hz) for up to 200 Mbps, and a PLC 10/100 Ethernet port using a RJ45 connector. The ASUS can communicate up to approximately 300 meters, covering a 465 square meter home, and uses 128-bit Advanced Encryption Standard (AES) for the encryption of data. Quality of Service is implemented through IEEE 802.1p. The RAMOS Mini C, shown in Figure 21, is the sensor control module in each home. It connects to a network, sensors, and a power supply, and costs around €400 (www.conteg.com). The device has 4 inputs and 2 outputs, connecting up to 4 sensors at a time, each with a unique sensor ID (e.g. flood, motion, front door, and fire). The output contact switch can send email or SMS alarms to several recipients (e.g. caregivers and technical partners).

Figure 20 Ethernet network adapter bridge [282]

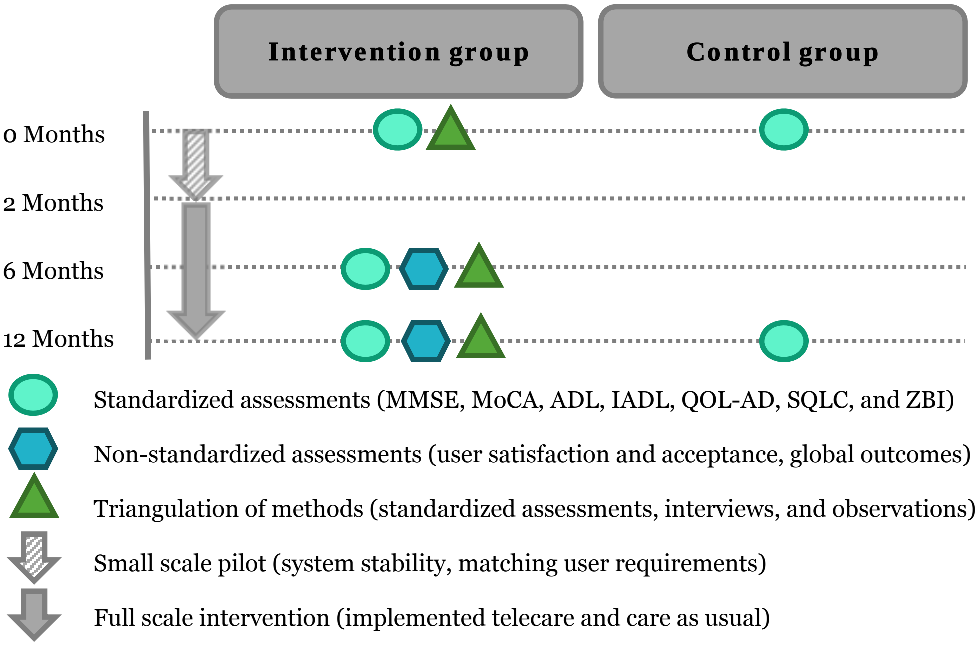
Figure 21 Sensor control module [282]

The primary objective of the integration tests were to ensure that HW and SW components will perform properly and that the ISISEMD platform is capable of successful functioning. The technical components of the system were successfully integrated, tested, and implementation and training were effectively carried out. The next phase of the project involves validating the system in real-life deployment.

4.3 Assessment methods

A comparative analysis of the data between the intervention and control groups helps to draw quantifiable conclusions on the usefulness of the intervention. When aiming to increase quality of life, a relativist validation is a continual method that accumulates knowledge on the outcomes, including heuristic and non-precise outcomes. In engineering design and palliative intervention research, problems do not have a single best solution and draw from multiple disciplines to provide solutions. Attempting to only use objective standards to understand the effectiveness of gerontechnology in dementia care is unsupported [160] [283], so relative validity (contextual usefulness) is also a studied outcome. Quantitative evaluations can validate the intervention objectives, but can fail to validate the external relevance, thereby making generalizations weaker by not addressing the intervention's usefulness [160]. Figure 22 depicts the evaluation timeline for the ISISEMD project.

Figure 22 Testing and evaluation time schedule



The regional partners, who recruited participants, helped to install the equipment in the homes, train the participants, and administered the user evaluations throughout the trial. The data is reported by the interviewers, who were the professionals or students in the regions. The information is coded and entered into spreadsheets that the project participants have access to. When the scanned assessments are available to the assessment team, the results are double checked. Participants were ordered by the date of joining the study in each region; the data is coded as follows:

- EP FR 01 represents the Elderly Person with dementia in Frederikshavn, Denmark in dyad 1
- ICG BEL 02 represents the Informal Caregiver in Belfast, North Ireland in dyad 2
- LAPP FCG 03 represents the Formal Caregiver in Lappeenranta, Finland for dyad 3
- TR 04 represents dyad 4 in Trikala, Greece
- BEL EP01, Baseline ADL would indicate the baseline ADL score of the older person in Belfast dyad 1

When unprompted or additional information is conveyed to the interviewers or professional caregivers, they are usually noted and available to the project's assessment team. Unintended and adverse effects were communicated to the project partners and remedied to the extent possible. While information related to the assessments and qualitative information on the living and care situation are mostly handwritten notes, information related to the services and technology are addressed through the Help Desk and ticketing system.

Among the participants, there are expected to be differences in beliefs on the stigma of dementia, coping strategies, levels of awareness, and personality traits that affect how the person views their situation. The participant experience will be shaped by their expectations, observations, and personal values. Since researching intervention outcomes in dementia care is multifaceted, it is helpful to elicit evaluation information from various angles. Different methods expose several attributes of the situation, and together provide more information with which to interpret the outcomes. User requirements were collected through a triangulation of methods (standardized questionnaires, semi-structured interviews, and professional observations), which were used for service development. The process evaluation is based on data gathered from the telecare system and through questionnaires and interviews administered before the technology was installed, approximately six months after installation, and again at the end of the 15 month trial (this analysis examines only pretest-posttest). Statistical analysis was carried out through Excel 2010 and Mat Lab R2012b, and consisted of *t*-tests and Pearson's correlations. National experts in the four countries were consulted regarding standardized assessments to use in the research project:

Denmark
- Dr. Bodil Gramkow Andersen, Chief Physician at the Department of Psychiatry and Gerontology
- Kasper Jørgensen, neuropsychology consultant, from the National Research Center for Dementia

Finland
- Olli-Pekka Ryynänen, Professor and leading researcher in quality of life testing at the University of Kuopio

Greece
- Ms. Sakka, external scientific advisor for the project
- Ms. Areti Efthymiou, Chairwoman of Athens Association of Alzheimer's Disease

North Ireland
- Dr. David Craig and Dr. Ben Knapp, consultants from the Memory Clinic at Belfast City Hospital and Senior Lecturers at the Queen's University, Belfast

When carrying out the initial interviews to determine user requirements, semi-structured interviews and observations were conducted simultaneously and complemented each other. The interviews were a fast, structured way to elicit the desired information, but it was easy for participants (particularly the person with dementia) to conceal difficulties they did not want to discuss. The observations made it easy to distinguish the environmental and functional problems in the home, and it was easier to visualize subsequent solutions that would be appropriate. The observations were an effective method, but were time consuming and are susceptible to weakness if the dyad is "performing" during the interview, and if the observer is seen as an obtrusive element of the context. A known challenge in this type of research, the methods to obtain the information affects the information itself [284] (i.e. they provide information only on the defined constructs, interviewer bias, Hawthorne effect). The assessments are summarized in Table 8, additionally described in Paper D,and the full questionnaires can be found in Appendix 2.

Table 8 Summary of the assessment questionnaires used in the clinical trial [273]

Variable	Tools	Example of what is evaluated	Score range	Score interpretation
Cognition	MMSE	Changes in cognition, memory, orientation, and visuo-construction	0 to30	≥26 = Normal 19-25,5 = Mild impairment 10-18,5 = Moderate impairment 0-9,5 = Severe impairment
	MoCA	Milder changes in cognition, attention, abstraction, and delayed recall	0 to30	≥ 26 = Normal 19-25,5 = Mild impairment 10-18,5 = Moderate impairment 0-9,5 = Severe impairment
Physical functioning and independence	ADL	Bathing, eating, continence, and basic physical functioning independence	0 to 6	Higher score = higher independence 3-4 = moderate dependence 0-2 = severe dependence
	IADL	Food preparation, medication management, and higher level physical functioning independence	0 to 8	Higher score = higher independence
Quality of life	QOL-AD	QOL of person with dementia, health, living situation, and ability to do things for fun	13 to 52	Higher score = higher quality of life
	SQLC	QOL of the caregiver, professional activities, social and leisure activities, and caregiving responsibilities	0 to 149	141-149 = Effective adaptation of the caregiver 100-140 = Mild effect on QOL 86-99 = Moderate effect on QOL <85 = Severe effect on QOL
Caregiver burden	12-item ZBI	Personal strain and role strain	0 to 48	Higher score means higher burden ≥17 = clinically significant burden

Assessment of cognitive functioning of the older adult with dementia

To assess cognitive functioning, the most widely used assessment form is the Folstein Mini-Mental Status Examination, or MMSE [285]. The MMSE assesses attention, naming, following instructions, language, memory, visuo-construction, and orientation. Questions include asking the patient to count backward from 100 by 7s, to repeat a short phrase after the examiner, and to draw a clock face and geometric figure. Since the MMSE is so commonly used, the interviewers in the regions were already trained in administering this assessment, which takes around 10 minutes. Authorized translated versions of the MMSE are available in Danish, Finnish, Greek and UK English. The MMSE is best suited for determining global cognitive functioning, and has demonstrated a specificity of 96,8%, but has a low sensitivity (71,8%) to Alzheimer's disease and other dementias (59,8%) [286]. The MMSE is reported to have a low sensitivity to mild cognitive impairments (18%), so a secondary cognitive assessment that is sensitive to mild cognitive impairments (90%) [287] is used to evaluate the level of cognitive functioning [287]. This secondary assessment, the Montreal Cognitive Assessment (MoCA) [288], screens for mild changes in attention, concentration, executive functioning, language, conceptual thinking, calculations, memory, visuo-construction, and orientation. MoCA has a sensitivity of 90% and a specificity of 87% to detect mild cognitive impairments; furthermore, the sensitivity and specificity for detecting early Alzheimer's disease is reported at 100% and 87%, respectively, and the internal consistency of MoCA is reported at α=0,83 [287]. The MoCA assessment is designed to be administered by any type of caregiver and takes around 5 minutes; furthermore, it is available free on the Internet and has been validated in over 20 languages, including the 4 languages used in the project.

Assessment of physical functioning of the older adult with dementia

The Katz's Activities of Daily Living (ADL) [289] and Lawton and Brody's Instrumental Activities of Daily Living (IADL) [290] are two extensively used assessments for physical functioning in older adults. The test-retest reliability is reported as κ=0,76 for ADL, and κ=0,88 for IADL [262]. The ADL assessment consists of 6 items that are binary (dependent or independent) and takes around 5 minutes to administer. A score of 0 indicates greater physical dependence and 6 indicates greater independence, with a score of 4 as the cut-off for moderate dependence and a score of 2 for severe dependence. The IADL scale takes around 10 minutes to administer, and is 8 items that are also rated as dependent or independent, a score of 0 indicates greater functional dependence and with a score of 8 indicating greater independence. Both assessments have been correlated to the need for long-term care and to quality of life [45]. The results are obtained via observations from the formal caregivers (i.e. occupational therapists or other skilled professional) and supplemented by the informal caregivers when needed.

Activities of Daily Living (ADL) assesses physical independence in:

a. Bathing
b. Dressing and undressing
c. Using the toilet
d. Transferring from bed or chair
e. Continence
f. Eating

Instrumental Activities of Daily Living (IADL) assesses functional independence in:

a. Using the telephone
b. Shopping
c. Food preparation
d. Maintaining the house (housekeeping)
e. Laundry
f. Using transportation
g. Medication management
h. Financial management

Assessment of quality of life

Quality of life is recognized as one of the most important indicators of the impact of dementia care interventions [199]. Improving quality of life is a central goal of interventions in dementia care (as well as strengthening cognitive and functional ability, moderating psychological and behavioral symptoms, and postponing further decline, which are believed to influence overall QOL). The standardized assessment of quality of life for attempts to portray an objective picture of the individual's quality of life by eliciting evaluations of domains that are found to be influential on overall quality of life in people with dementia.

The quality of life of the individual with dementia was measured through the most widely used dementia-specific measure [211], the Quality of Life – Alzheimer's disease (QOL-AD) questionnaire [178]. Translations and cultural adaptations are available in Danish, English for the UK, Finnish, and Greek by the Mapi Research Trust [207] [291]. The reliability is reported to have a Cronbach's range of 0,83 to 0,90 [178], and the agreement between the patient and proxy ratings has been reported as $p<0{,}01^{**}$ [98]. The QOL-AD is administered to both the older adult (EP) and the caregiver (ICG) in efforts to obtain a more accurate portrayal of life quality by not using the person with dementia's assessment alone, as they may not have awareness of their living situation (i.e. anosognosia), and also by not using the proxy (i.e. ICG) assessment alone, as proxies have a tendency to rate lower than the person with dementia themselves [177] [181] [182] [292]. Because it is an evaluation of the individual with dementia's life quality, their score is weighted by doubling the score before averaging with the caregiver's score [181] [212]:

$$\frac{EP + EP + ICG}{3} = Weighted\ QOL - AD\ score$$

The previous section on quality of life revealed that people with dementia have identified domains that are important to them [177] [181] [182]. The QOL-AD is found to include several of the self-identified important domains of QOL, and when combined with incorporating patient and proxy evaluations, good psychometrics, and easy administration, the QOL-AD tool is recommended for use in longitudinal studies [181]. The assessment takes 5-15 minutes to complete, consists of 13 items that are rated on a 4-point Likert scale from poor to excellent, and total scores range from 13-52 with higher scores indicating higher quality of life.

Quality of Life – Alzheimer's disease (QOL-AD) assesses the domains of:

1. Physical health
2. Energy (physical and mental health)
3. Mood (physical and mental health, affect)
4. Living situation (attachment, security and personal privacy)
5. Memory (mental health)
6. Family (attachment, social contact)
7. Marriage (attachment)
8. Friends (social contact)
9. Self as a whole (self-esteem/image)
10. Ability to do chores around the house (ability to contribute, being useful)
11. Ability to do things for fun (leisure, enjoyment of activities)
12. Money (financial situation)
13. Life as a whole

Caregiver quality of life is measured through the Scale of Quality of Life of Caregivers (SQLC) questionnaire [293]. The assessment consists of 16 questions that evaluate the professional activities, social and leisure activities, and caregiving responsibilities. Scores range from 0-149 and higher scores indicate higher quality of life. The authors of the scale find that 141-149 points mean full adaptation of the caregivers, 100-140 points mean mild disadaptation, 86-99 points mean moderate disadaptation, and less than 85 points means severe disadaptation. The internal consistency has been reported as high, α=0,87 [294].

Scale of Quality of Life of Caregivers (SQLC) assesses:

- professional activity of the caregiver (work and volunteering)
- social and leisure activities (family and friends, attending events)
- responsibilities of the caregiver (tasks to ensure the daily activities of the person with dementia)

Caregivers of individuals with dementia often experience stress related to the responsibilities of caregiving tasks (i.e. lack of time for self) as well as from the natural psychosocial involvement of the relationship (i.e. feelings of guilt). To measure the level of caregiving-related stress, the Zarit Burden Interview short form (ZBI) is used [295]. It is a 12-item assessment where answers are given on a 5-point Likert scale of 0 (never) to 4 (nearly always). The ZBI has been the most frequently studied and used burden measurement instrument in the caregiving literature [295] [296] [297] [298]. The 12-item ZBI is endorsed as the best short-form version to use [299], and is reported to have an internal consistency of α=0,88 [295], Bédard and colleagues cautiously suggested that a score ≥ 17 on the ZBI short form is suggestive of clinically significant caregiver burden [295]. However, since the ZBI is used as a continuous measurement instrument (to assess the care interventions) rather than as a screening instrument for diagnosing caregiving-related depression, a cut off score is not used in this research. It is mentioned here as an indicator of what is considered in the medical research field as a significantly high level of caregiving-related stress. The assessment has been translated by the Mapi Institute [204] into English for the UK, Finnish, and Greek; the Danish version was translated from English by the regional partners and the National Research Center for Dementia in Copenhagen.

Zarit Burden Interview, short form (12-item ZBI) assesses care-related stress in the following:

1. Time for self
2. Stress between roles
3. Feelings of anger
4. Effects on other relationships
5. Feeling strained
6. Effects on health
7. Privacy
8. Social life
9. Feeling loss of control
10. Feelings of uncertainty
11. Feelings of guilt
12. Feeling inadequate

In addition to the standardized assessment tools, the project partners also inquired about the global quality of life of the end users by asking additional questions to the intervention group in order to elicit global outcome indicators. The additional questions provide information on the perceived efficacy of the system. These questions are not standardized or validated, and were designed to supplement in the data in the ISISEMD research project [281]. The purpose of using the qualitative questions is to complement the statistical analysis and to provide initiation as to what factors may be influencing intervention participants' quality of life and why. The exact additional questions and informal interviews are not recommended for direct use in other studies; however, it is beneficial to further develop methods to elicit additional information from participants for a more holistic evaluation of the intervention. The questionnaire is based on the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0) [300] and the Everyday Technology Use Questionnaire (ETUQ) [301]. QUEST 2.0 can be used to evaluate an individual's satisfaction with their use of an Assistive Technology Device (ATD) without the requisite of considering device performance. The ISISEMD system is not a single ATD so the QUEST 2.0 questionnaire is not directly used, but serves as a model [272]. ETUQ has been developed to map perceived relevance and competence of use for everyday technologies for aging adults with cognitive impairment; however, it evaluates commonly used technology and not necessarily assistive or telecare technology and is therefore also used as a model for the ISISEMD global questions [272]. The following global questions will be addressed in this thesis:

1. Your overall change in feeling of quality of life by using the services
    3. It increases more than I thought it would
    2. It increases
    1. No change, no influence
    0. It decreases

2. Overall change in feeling of quality of life for your relative by using the services
    3. It increases more than I thought it would
    2. It increases
    1. No change, no influence
    0. It decreases

3. Overall support in independent living by using the services
    3. It increases more than I thought it would
    2. It increases
    1. No change, no influence
    0. It decreases

4. Your overall feeling of care responsibilities by using the services
    3. It decreases more than I thought it would
    2. It decreases
    1. No changes, no influence
    0. It increases

5. Your overall feeling of safety about the home environment
    3. I feel significantly safer
    2. I feel safer
    1. I do not feel safer
    0. I feel less safe

6. Your overall feeling of satisfaction about the system
    3. I am more satisfied than I thought I would be
    2. I am satisfied
    1. I am not satisfied
    0. I am disappointed

7. Would you want to use a system like this one after the study?
    3. I definitely would use a system like this
    2. I would consider using a system like this
    1. I would not consider using a system like this
    0. I would not use a system like this

8. Would you be willing to pay for a service system like this?
    3. I would definitely pay for all of these services
    2. I would definitely pay for some of these services
    1. I would consider paying for some of these services
    0. I would not pay for these services at all

The tools used for validation, and hypothesized outcomes are presented in Table 8, above. The measurement instruments have been selected based on their appropriateness and feasibility for the research, and on their psychometric properties. Table 9, below, summarizes the standardized instruments used, primary and secondary outcomes, and how significant results will be determined.

Table 9 Research questions and methods to validate outcomes

Research question	Variable and outcome	Assessment for validation	Method of aggregation	Hypothesized outcome
1. Will using gerontechnology have positive effects on physical and independent functioning?	Physical and independent functioning Secondary outcome	ADL and IADL	Compared means between groups	H_1: Intervention group will show improvement or less decline than the control group H_0: Intervention group shows no significant difference from the control group
	Physical and independent functioning Secondary outcome	Non-standardized questionnaire on feeling of change in independent living	Mean post hoc from intervention group	H_1: Intervention group will report an increase in independent living H_0: Intervention group will report no change or decrease in independent living
2. Will using gerontechnology have positive effects on QOL in the person with dementia?	Quality of life Primary outcome	QOL-AD	Compared means	H_1: Intervention group will show improvement or less decline in QOL-AD than the control group H_0: Intervention group shows no significant difference from the control group's QOL-AD
	Quality of life Secondary outcome	Non-standardized questionnaire on feeling of change in QOL	Mean post hoc from intervention group	H_1: The intervention group will show an increase in QOL for 50% of participants with dementia H_0: Intervention group will report no change or decrease in QOL
3. Will using gerontechnology have positive effects on QOL in the caregivers?	Quality of life Primary outcome	SQLC	Compared means	H_1: Intervention group will show improvement or less decline in SQLC than the control group H_0: Intervention group shows no significant difference from the control group's SQLC
	Quality of life Secondary outcome	Non-standardized questionnaire on feeling of change in QOL	Mean post hoc from intervention group	H_1: The intervention group will show an increase in QOL for 70% of caregivers H_0: Intervention group will report no change or decrease in QOL
4. Will using gerontechnology have positive effects on caregiver burden?	Caregiver burden Secondary outcome	ZBI	Compared means	H_1: Intervention group will show improvement or less decline in ZBI than the control group H_0: Intervention group shows no significant difference from the control group's ZBI
	Caregiver burden Secondary outcome	Non-standardized questionnaire on feeling of change in care responsibilities	Mean post hoc from intervention group	H_1: The intervention group will show reduced care responsibilities by 60% H_0: Intervention group has no effect on or increases care responsibilities
5. Will using gerontechnology have positive effects on safety in the home?	User acceptance Secondary outcome	Non-standardized questionnaire on feeling of safety in the home environment	Mean post hoc from intervention group	H_1: Participants will report feeling safer with the telecare system H_2: The intervention group will show an increase in feeling of safety in 30% of participants H_0: Intervention group has no effect on or decreases feeling of safety
6. Will people be satisfied with the intervention system?	User satisfaction Secondary outcome	Non-standardized questionnaire on feeling of satisfaction regarding the system	Mean post hoc from intervention group	H_1: Participants will report being satisfied with the telecare system H_2: 75% of participants will report being satisfied with the telecare system H_0: Intervention group has no effect on or increases care responsibilities
7. Will end users be willing to pay for gerontechnology services?	User acceptance Secondary outcome	Non-standardized questionnaire on willingness to pay for services.	Mean post hoc from intervention group	H_1: Participants will report willingness to pay for telecare services. H_0: Participants will not be willing to pay for telecare in place of usual care.
8. Would people want to use services like these?	User satisfaction Secondary outcome	Non-standardized questionnaire on willingness to use services.	Average of post hoc responses	H_1: Participants will report a desire to continue using telecare services. H_2: 75% of intervention caregivers will report a desire to continue using services H_0: Participants will not want to continue using telecare services.

Methodology summary:

This chapter described the methodology used to develop and test the telecare services for dementia care. When using technologies in real-life, longitudinal application, there is a growing awareness in developing individualized assessment tools. In dementia care research, personalized assessments would support the phenomenological view that quality of life is unique to the individual. However, the administration and scoring for the vast majority of quality of life assessments are still not digitized, is time consuming, and is outdated (e.g. pen-and-paper testing of cutting-edge technologies) when compared to the modern technologies they evaluate. To promote personalized assessments, computerizing them would be a good start. A literature review in Paper E revealed that there were no QOL tools that were dementia-specific and allow for telecare impact. Several of the papers discuss the speculative development of a prototype that could be integrated in dementia care as part of the Assistive Technology services (Papers B, E, and F).

The principal summary measures are based on the difference in means between two assessment points or two groups. A thorough assessment, although somewhat limited in the scope of the content of the questionnaires, evaluates the statistical significance of the changes. Overall, this research takes a holistic view on quality of life, and that QOL is potentially influenced by all the domains assessed, so outcomes in any of the assessments are theorized to affect overall QOL (i.e. indicators of quality of life). The criteria for participants and how they were recruited was given. The telecare system and service components were described, with examples from the project to illustrate. The standardized assessment tools that were used to measure change in quality of life over the course of the research trial were also presented, naming which parameters are evaluated, and reporting psychometrics. Finally, non-standardized questions that were posed to the end users on their global feelings of change from using technology during the project were given.

Papers supporting Chapter 4:

Paper B supports this chapter by discussing a prototype for an electronic quality of life assessment for use in dementia care. Paper D describes the ISISEMD development, implementation, and evaluation methods, and by explaining the services. This paper also describes baseline and intermediate results of the trial. Paper E reports a literature search for dementia-specific quality of life assessment tools that could be used to evaluate telecare impact. This paper also considers revisions to the proposed electronic QOL assessment prototype. Paper F presents a cutting-edge description of gerontechnology use, evaluation, and continued development that is accelerated through advancements in technology, indicating a need for electronic QOL assessment methods. Papers G and H additionally describe the ISISEMD methodology.

Chapter 5. Evaluation of the outcomes

This chapter describes the analysis to evaluate the outcomes of a gerontechnology intervention in dementia care. The data is analyzed by comparing the intervention to the control group (i.e. differences between groups) through independent *t*-tests, and by looking for significant changes within the intervention and control groups (i.e. within group differences) through paired *t*-tests. These tests are made both at the group level and at the country level. Pearson product-moment correlation coefficient tests evaluate the strength of the linear interdependence between two variables, e.g. ZBI and IADL. In addition to comparing the baseline and final scores of the control and intervention groups, subgroup analyses will provide additional exploratory data on the intervention outcomes. A deeper analysis of the data involves apportioning the intervention and control groups by variables to test for significant associations and correlations. This is done by taking the median value, such as median age, and analysing the results of the younger and older participants. All tests are run with $\alpha=0{,}05$ and 2-tails, and the 95% Confidence Intervals (CI) are based on a student's t-distribution rather than a normal distribution as the true population standard deviation is unknown. The results of p-values $\leq 0{,}05$ indicate a significant probability, and p-values $\leq 0{,}02$ indicate highly significant probability, denoted by * and **, respectively. As Denmark did not have a control group of participants, some results include the total intervention population (incl. DK) as well as with the Denmark sample removed (excl. DK). The results of the non-standardized questionnaires are presented and compared to the standardized outcomes. A qualitative analysis is given on the intervention group participation, outcomes, and implications.

Papers included in Chapter 5:

Paper D includes the mid-term evaluation of the ISISMD project and qualitative results from the participants.

> Paper D: Anelia Mitseva, Carrie Beth Peterson, Christina Karamberi, Lamprini Ch. Oikonomou, Athanasois Mpallis, Charalampos Giannakakos, and George E Dafoulas. "Gerontechnology: Providing a helping hand when caring for cognitively impaired older adults – intermediate results on the satisfaction and acceptance of informal caregivers from a controlled study." *Current Gerontology and Geriatrics Research*, Hindawi Publishing, Article ID 401705, 2012. DOI: 10.1155/2012/401705. 19 pages.

Paper E discusses issues in assessing quality of life outcomes as a result of technology interaction and presents qualitative results from the research.

> Paper E: Carrie Beth Peterson, Neeli R Prasad and Ramjee Prasad. "Assessing assistive technology outcomes with dementia." *Gerontechnology 11(2)*, p. 259. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.414.740. 10 pages.

Paper G specifically addresses the outcomes in caregiver burden, including qualitative information.

> Paper G: Carrie Beth Peterson, Lars Bo Larsen, Poul Svante Eriksen and Ole K Hejlesen. "Zarit burden interview shows decrease in caregiver burden with technology intervention in European dementia study." Submitted for publication to the *British Medical Journal*, 20 pages, 2014.

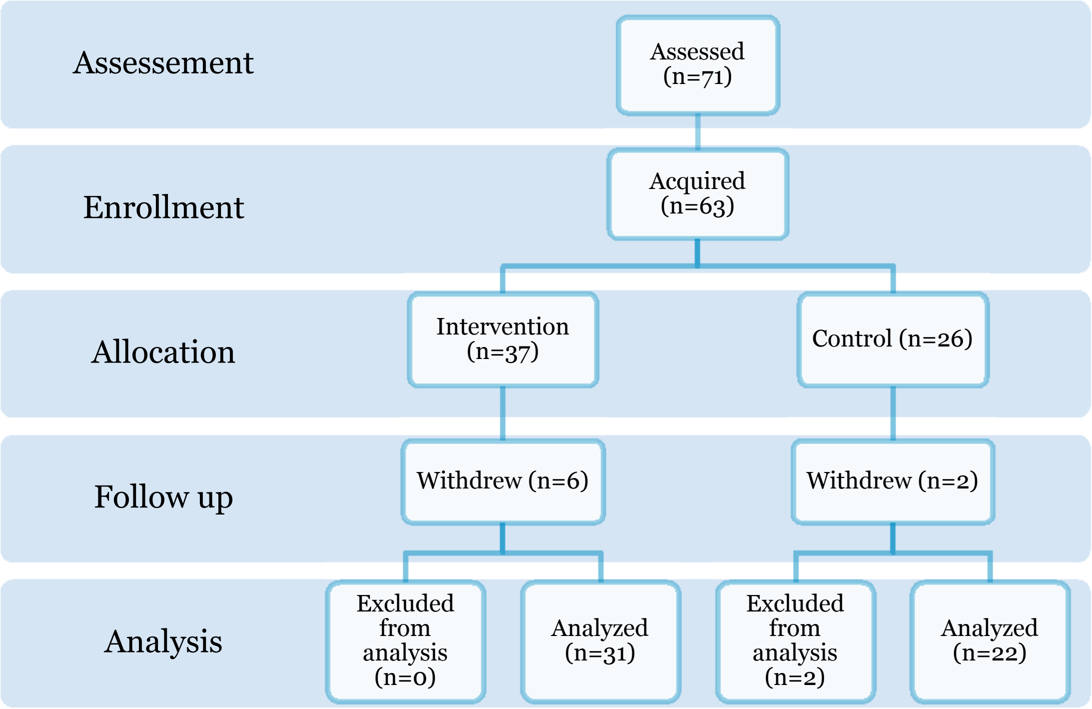
Paper H focuses on outcomes in caregiver quality of life.

> Paper H: Carrie Beth Peterson. "Results from a clinical trial on gerontechnology in dementia care and caregiver quality of life outcomes." Technical report, 8 pages, 2013.

5.1 Description of the participants

To treat the data, the responses from the assessments were transferred from the raw form (i.e. copies from the regions) to a master assessment in English. This ensured that the data was uniform before being analyzed. Figure 23 shows the participant flow from enrollment to analysis. Of the n=55 dyads, a further 3,6% (n=2) are removed from the control group in a list-wise deletion, resulting in 84,1% (n=53) which have complete data sets for analysis. Missing data is considered missing at random (i.e. reporting errors or otherwise missing scores) and is therefore treated with list-wise deletion so that only available data is analyzed for comparison. It is not hypothesized that the intervention would have a significant effect on cognition scores; therefore, incomplete MMSE and MoCA data do not exclude participants during the list-wise deletion. There are n=31 in the intervention group, and n=22 dyads the control group that are available for analysis (i.e. baseline and final for assessments for physical functioning, independent functioning, quality of life of the person with dementia, quality of life of the caregiver, and caregiver burden).

Figure 23 Participant flow diagram (by dyads) [273]



The participants are 66% female, and 41,5% of the participants with dementia live alone. Just under half of the caregivers are children of the individual with dementia, 37,7% are spouses, and 13,2% have another type of relationship (i.e. neighbor, friend, or other relative). Further descriptive statistics on the participant population are given in Figure 24, Table 10 and Table 11.

Figure 24 Gender, care relationship, and living arrangement of the participants, by number

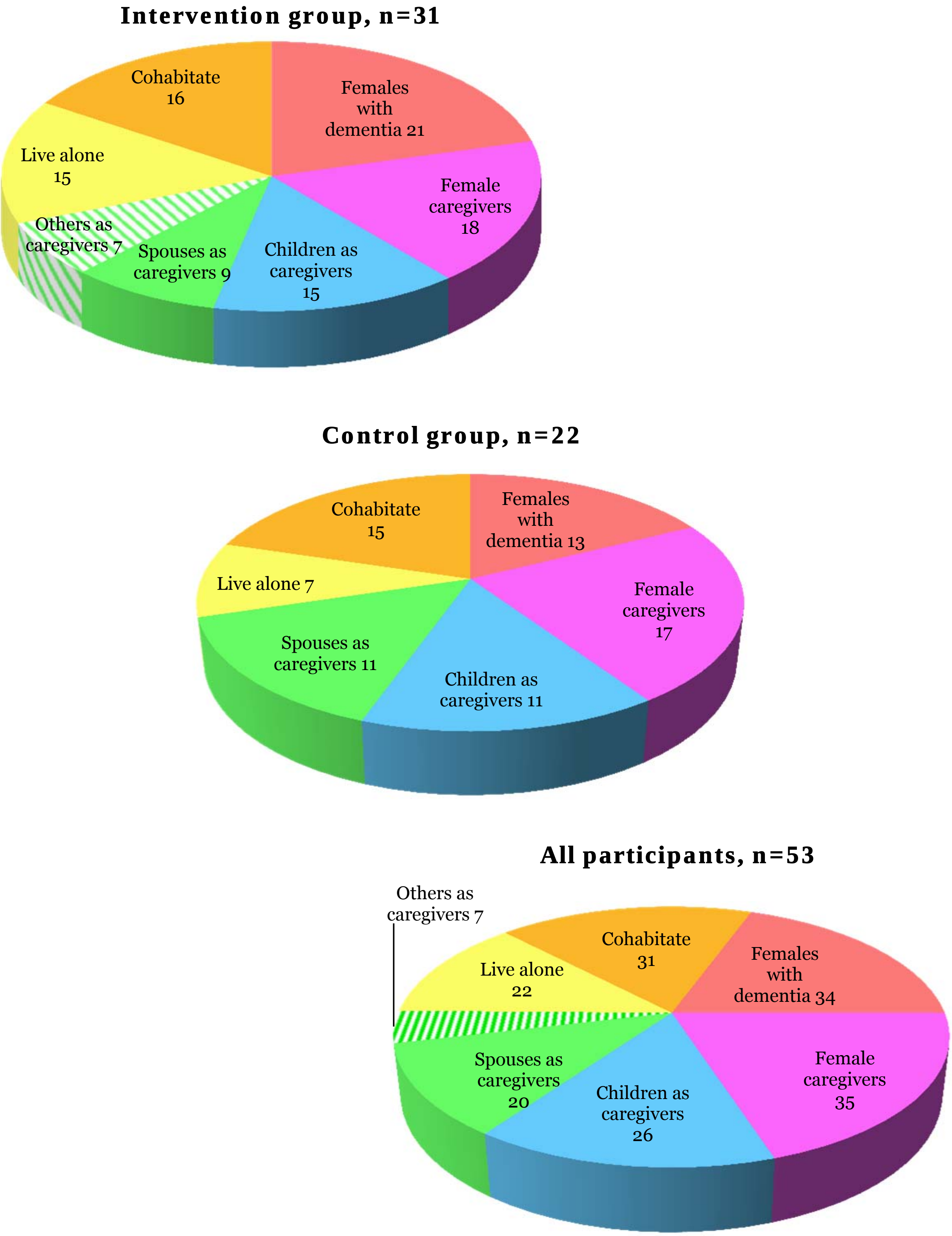


Table 10 Descriptive statistics of the control group at baseline, n=22

	MMSE	MoCA	ADL	IADL	QOL-AD	SQLC	ZBI	EP Age	ICG Age
	n=22	n=21	n=22	n=22	n=22	n=22	n=22	n=22	n=22
Mean	22,95	17,90	5,59	4,95	33,68	90,73	12,45	80,64	63,23
Median	22,50	18,00	6,00	5,50	33,83	92,00	11,50	81,50	62,50
Mode	29,00	18,00	6,00	6,00	35,00	103,00	10,00	80,00	57,00
Standard Deviation	5,07	3,71	0,85	2,19	6,31	13,12	8,92	7,56	14,02
Standard Error	1,08	0,81	0,18	0,47	1,35	2,80	1,90	1,61	2,99
Sample Variance	25,66	13,79	0,73	4,81	39,80	172,02	79,50	57,19	196,66
Kurtosis	-1,63	-1,05	3,50	-0,33	-1,03	-1,07	1,26	0,88	-0,81
Skewness	0,14	0,15	-2,08	-0,50	0,15	0,06	1,05	-0,76	-0,10
Range	14,00	12,00	3,00	8,00	21,00	41,00	34,00	32,00	47,00
Minimum	16,00	12,00	3,00	0,00	23,67	72,00	0,00	62,00	37,00
Maximum	30,00	24,00	6,00	8,00	44,67	113,00	34,00	94,00	84,00
Sum	505,00	376,00	123,00	109,00	741,00	1996,00	274,00	1774,00	1391,00

Table 11 Descriptive statistics of the intervention group at baseline, incl. DK n=31

	MMSE	MoCA	ADL	IADL	QOL-AD	SQLC	ZBI	EP Age	ICG Age
	n=29	n=28	n=31	n=31	n=31	n=31	n=31	n=31	n=27
Mean	22,07	16,89	5,26	4,39	34,32	84,48	16,42	77,32	54,26
Median	22,00	17,50	6,00	4,00	35,00	85,00	16,00	75,00	55,00
Mode	23,00	16,00	6,00	4,00	34,67	92,00	9,00	75,00	57,00
Standard Deviation	3,99	4,43	1,24	1,69	5,78	20,33	8,80	7,02	12,94
Standard Error	0,74	0,84	0,22	0,30	1,04	3,65	1,58	1,26	2,49
Sample Variance	15,92	19,65	1,53	2,85	33,41	413,12	77,52	49,29	167,51
Kurtosis	-0,27	-0,05	10,58	-0,08	-0,18	0,44	-0,54	-0,89	-0,16
Skewness	0,39	-0,27	-2,90	0,36	-0,19	-0,67	0,07	0,13	0,36
Range	15,00	19,00	6,00	7,00	22,33	83,00	33,00	26,00	52,00
Minimum	15,00	7,00	0,00	1,00	23,00	33,00	0,00	65,00	30,00
Maximum	30,00	26,00	6,00	8,00	45,33	116,00	33,00	91,00	82,00
Sum	640,00	473,00	163,00	136,00	1063,83	2619,00	509,00	2397,00	1465,00

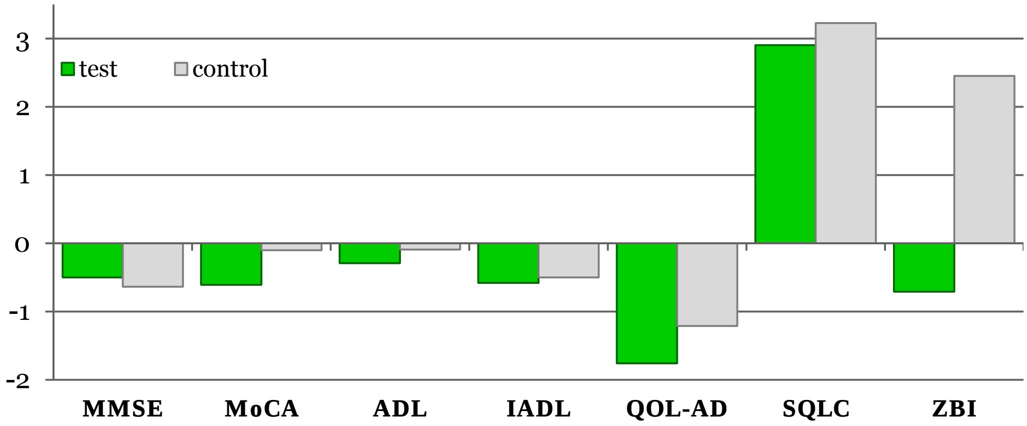
There are some differences in the basic data on the assessment outcomes between the intervention and control groups. Average decline in cognition measured by MMSE is expected around 2-4 points per year [285] [302], and both of the control and intervention group participants exhibit less than previously reported cognitive decline. The control group exhibits more decline in MMSE, but less decline in MoCA than the intervention group. This could be expected if the intervention group had milder forms of dementia (which MoCA is sensitive to). The control group has higher cognition mean scores in both assessments, and at both evaluation times. The individual MMSE scores range from moderate to no impairment, but this is still acceptable to the study, as it is known that some individuals who have impairment may score within normal ranges on cognitive assessments. The mean MoCA scores meet the criteria for moderate impairment, and the individual scores range from severe to no impairment, both are considered acceptable for the study since the MoCA test is not the primary cognitive assessment, and is known to be more sensitive. The one participant who scored 7 on the baseline MoCA also scored 23 on the MMSE during the same assessment period, and the two participants who scored 9 on the final MoCA also scored 19 and 23 on the final MMSE.

The control group has higher ADL and equal or higher IADL scores; the intervention group shows more decline than the control group in both assessments. Research shows that when the person with dementia has higher levels of dependence (physical and cognitive), caregivers tend to have higher levels of burden [82] [86] [87]; therefore, it could be expected that the intervention group caregivers would have higher ZBI scores. When looking at the data, the intervention group does show higher caregiver burden at both baseline and final assessments. Quality of life is also associated with abilities, dependence, and caregiver burden. The results show that the intervention group has higher QOL-AD scores at both evaluation times, but experienced more mean decline than the control group. Conversely, the control group has higher SQLC scores at both evaluations and experienced more mean improvement than the intervention group. While the quality of life score outcomes are the opposite of what is hypothesized, the data analysis between the two groups will expose if these differences are statistically significant.

5.2 Analysis of the difference between intervention and control groups

Having n=53 dyads attains a power of 35% when testing between groups. No significant differences were found between the intervention and control group assessment scores at baseline; however, there are some possible confounding variables which may present bias at the study level and influence the outcomes. The control group caregivers are an average of 8,97, years older (p=0,02**), and half are spouses. The average caregiver is an adult female relative of the person with dementia [78] [217]; both wives and daughters are at risk for experiencing caregiver burden. Middle-aged caregivers are in the sandwich generation, meaning they likely care for both their parents and their children. Caregivers with high levels of burden are more likely to seek out formal support services, so it is possible that there is a degree of self-selection among the intervention group caregivers participation due to higher levels of burden. Younger cohorts are statistically higher users of advanced technology [303], and could be more motivated to join a telecare study. However, caregivers as a whole are known to be higher technology users than the general population, and are more likely to use the internet for health-related activity [303]. The difference in caregivers between the two groups is assumed to be representative of that which would occur in the general population and is therefore acceptable as interventions are aimed at supporting all caregivers for individuals with dementia. Figure 25 represents the mean change of each group's assessments from baseline to final evaluation.

Figure 25 Difference from baseline to final mean scores for the control and intervention groups, n=53



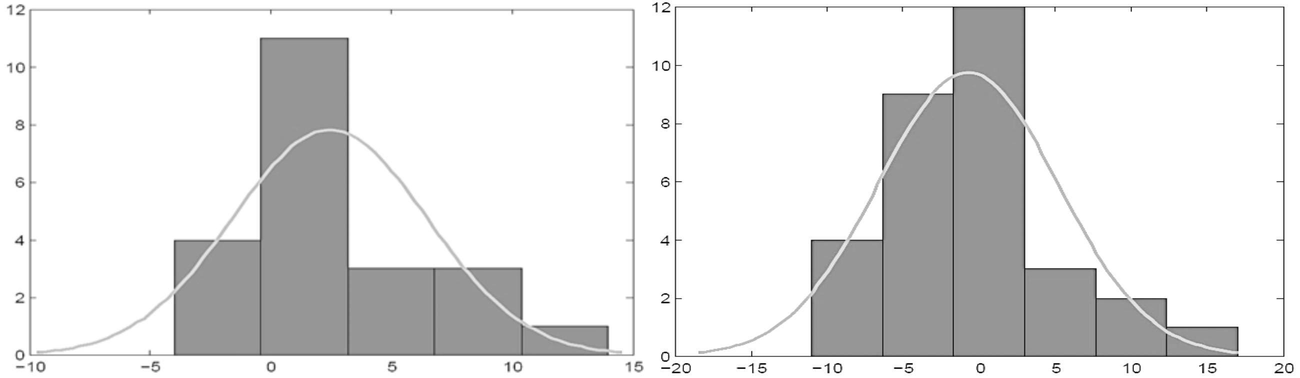
To observe whether or not gerontechnology has a positive effect, an analysis of the differences between the groups provides more information. The between groups *t*-tests are independent tests, meaning the scores in one sample (i.e. intervention group) are not dependent on the scores in the other sample (i.e. control group). The outcomes from the assessments are compared between the groups. Table 12 shows the results of the independent t-tests when the control group is compared to the intervention group, excluding Denmark. For significant results, the result including Denmark is also given.

Table 12 Results of independent *t*-tests between the control and intervention group mean changes, excl. DK n=47

Outcome tool	Outcomes between groups	Outcomes within groups
MMSE	p=0,75	Intervention declined (μ -0,91) Control declined (μ -0,64)
MoCA	p=0,57	Intervention declined (μ -0,61) Control declined (μ -0,10)
ADL	p=0,23	Intervention declined (μ-0,40) Control declined (μ -0,09)
IADL	p=0,53	Intervention declined (μ -0,76) Control declined (μ -0,50)
QOL-AD	p=0,36	Intervention declined (μ -2,36) Control declined (μ -1,21)
SQLC	p=0,61	Intervention improved (μ 1,44) Control improved (μ 3,23)
ZBI	p=0,02** (p=0,03* incl. DK)	Intervention improved (μ -1,00) Intervention improved incl. DK (μ -0,71) Control declined (μ 2,45)
Sum	**p=0,017** **(p=0,44 incl. DK)**	

Independent t-tests show that the two groups do not have significantly different outcomes from each other, except for in caregiver burden (ZBI). The statistical analysis shows that the caregivers who used the technologies have improvement in their caregiver burden while those in the control group show increased caregiver burden, and that this is the only significant result between the two groups. Histograms with the distribution fit are made for the assessment change from baseline in both groups and can be found in Appendix 6. Figure 26 shows the histograms for the control and intervention groups ZBI change from baseline to final assessment. This difference in caregiver burden is further examined as a comparative outcome of the intervention inPapers D and G.

Figure 26 Control and Intervention ZBI histograms with distribution fit [273]



Control group n=22

Mean change from baseline= 2,45
p=0,01**
95% CI [0,66 to 4,25]

Intervention group incl. DK, n=31

Mean change from baseline= -0,71
p=0,51
95% CI [-2,89 to 1,47]

T-tests are ran on the groups by country to look for significant differences. In North Ireland (n=15), the intervention group has significantly lower scores in SQLC (p=0,007**) and higher ZBI (p=0,002**) at baseline, and lower MMSE (p=0,05*) and IADL (p=0,03*) and higher ZBI (p=0,003**) scores at final assessment. There is only a significant difference in mean change in MMSE (0,03*); the aggregate difference between North Ireland control and intervention groups is non-significant (p=0,72). In Denmark (n=6), there is no control group to compare to and there were no significant outcomes found within the intervention group. Finland (n=16) has a significant difference in baseline QOL-AD (p=0,03*) between the two groups. There is a significant difference in QOL-AD (0,01**) and SQLC (p=0,04*) outcomes, the intervention group shows decline while the control group shows improvement in both. The aggregate difference between the control and intervention groups in Finland is non-significant (p=0,08). In Greece (n=15), there is a significant difference in baseline QOL-AD (p=0,02**), but not at final assessment; the control scores are higher, but show significant decline. In mean outcomes, there is a significant difference in MoCA (p=0,03*), QOL-AD (p=0,03*), and in ZBI (p=0,003**). The intervention group shows a highly significant improvement in ZBI (p=0,004**) while the control group shows a significant increase (p=0,05*). The control group also has a significant decline in QOL-AD (p=0,04*), but the aggregate difference between the two groups in Greece is non-significant (p=0,76). Paper D provides more discussion on the regional outcomes up through the mid-term evaluation.

Summary of the analysis between groups

Overall, the intervention produced an effect that is not significantly different from the effect of usual care on quality of life except for a highly significant difference in caregiver burden outcomes, and this is significant both with and without Denmark’s intervention group included. Within the countries, there is no significant difference in the overall outcomes between control and intervention groups.

5.3 Analysis of the difference within the intervention and control groups

The paired *t*-tests investigate if the baseline and final scores were significantly different from each other, presented in Table 13. Testing within the intervention group achieves a power of 67% (n=31), and n=22 participants achieves a power of 52% when testing within the control group. Both groups exhibit a significant decline in instrumental physical functioning (IADL). The intervention group further shows a significant decline in QOL-AD, and there is a highly significant increase in the control group's caregiver burden.

Table 13 Results of the paired *t*-tests on the differences from baseline to final scores

Assessment	Intervention Incl. DK n=31	Intervention Excl. DK n=25	Control n=22
MMSE	p=0,46	p=0,24	p=0,16
MoCA	p=0,29	p=0,36	p=0,87
ADL	p=0,13	p=0,09	p=0,33
IADL	p=0,05*	p=0,03*	p=0,03*
QOL-AD	p=0,04*	p=0,02**	p=0,16
SQLC	p=0,24	p=0,56	p=0,19
ZBI	p=0,51	p=0,35	p=0,01**
Overall	**p=0,75**	**p=0,19**	**p=0,51**

As physical functioning and independence has previously been correlated with caregiving-related stress, [82] [86] [87], the results indicate that the use of technology defers increases in caregiving-related stress despite an increase in caregiving responsibilities due to functional decline. This is examined further in Paper G. The IADL and ZBI scores are given in Table 14. The Standard Deviation (SD) shows the variation from the mean within the participant scores, and scores that are more than one SD away from the mean are significantly different. This data shows the variance of the population for a particular assessment. The Median Absolute Deviation (MAD) is the median of the absolute values of the deviations from the mean. This data shows the middle of the range of variation. And the Interquartile Range (IQR) shows the middle 50% when the total range is broken down into quartiles. Where the SD measures variation, the MAD measures central tendency, and the IQR measures variation within the middle 50% of scores. Table 15 presents an overview of the t-test results, both between and within the groups, which can also be found in Paper H.

Table 14 Results for IADL and ZBI and paired *t*-test significance [273]

Group	Measure	Baseline mean (SD)	Final mean (SD)	Mean change (MAD/IQR)	Significance of change
Control n=22	IADL	4,95 (2,19)	4,45 (1,97)	-0,50 (1/1)	0,03*
	ZBI	12,45 (8,92)	14,91 (8,55)	2,46 (2/4)	0,01**
Intervention incl. DK n=31	IADL	4,39 (1,69)	3,81 (1,85)	-0,58 (1/2)	0,05*
	ZBI	16,42 (8,80)	15,71 (9,13)	-0,71 (4/7)	0,51
Intervention excl. DK n=25	IADL	4,36 (1,52)	3,60 (1,83)	-0,76 1/2)	0,03*
	ZBI	19,20 (7,13)	18,20 (7,39)	-1,00 (4/7)	0,35
All incl. DK n=53	IADL	4,62 (1,91)	4,08 (1,91)	-0,55 (1/1)	0,005**
	ZBI	14,77 (8,98)	15,38 (8,82)	0,60 (3/5)	0,42
All excl. DK n=47	IADL	4,64 (1,87)	4,00 (1,92)	-0,64 (1/1)	0,003**
	ZBI	16,04 (8,62)	16,66 (8,04)	0,62 (3/5,5)	0,40

Table 15 Summary of the assessment score outcomes from baseline to final evaluation [304]

Assessment		Control n=22	Intervention incl. DK, n=31
MMSE	Range of scores	Baseline 16 – 30 Final 14 – 30	Baseline 15 – 30 Final 14 – 30
	Mean score	Baseline 22,95 Final 22,32	Baseline 22,07 Final 21,82
	Mean change within groups; [95% CI]; significance	-0,64; [-1,55 to 0,28] p=0,16	-0,50; [-1,85 to 0,85] p=0,46
	Difference between group mean outcomes; significance	0,14; p=0,87	
MOCA	Range of scores	Baseline 12 – 24 Final 11 – 29	Baseline 7 – 26 Final 9 – 29
	Mean score	Baseline 17,90 Final 17,80	Baseline 16,89 Final 16,29
	Mean change within groups; [95% CI]; significance	-0,10; [-1,36 to 1,16] p=0,87	-0,61; [-1,76 to 0,55] p=0,29
	Difference between group mean outcomes; significance	0,51; p=0,55	
ADL	Range of scores	Baseline 3 – 6 Final 3 – 6	Baseline 0 – 6 Final 0 – 6
	Mean score	Baseline 5,59 Final 5,50	Baseline 5,26 Final 4,97
	Mean change within groups; [95% CI]; significance	-0,09; [-0,28 to 0,10] p=0,33	-0,29; [-0,67 to 0,09] p=0,13
	Difference between group mean outcomes; significance	0,20; p=0,40	
IADL	Range of scores	Baseline 0 – 8 Final 1 – 8	Baseline 1 – 8 Final 0 – 7
	Mean score	Baseline 4,95 Final 4,45	Baseline 4,39 Final 3,81
	Mean change within groups; [95% CI]; significance	-0,50; [-0,95 to -0,05] p=0,03*	-0,58; [-1,16 to -0,001] p=0,05*
	Difference between group mean outcomes; significance	0,08; p=0,83	
QOL-AD	Range of scores	Baseline 23,67 - 44,67 Final 22,33 - 41,67	Baseline 23 – 45,33 Final 23 – 43,33
	Mean score	Baseline 33,68 Final 32,47	Baseline 34,32 Final 32,56
	Mean change within groups; [95% CI]; significance	-1,21; [-2,93 to 0,51] p=0,16	-1,76; [-3,39 to -0,13] p=0,04*
	Difference between group mean outcomes; significance	0,55; p=0,64	
SQLC	Range of scores	Baseline 72 – 113 Final 72 – 119	Baseline 33 – 116 Final 27 – 130
	Mean score	Baseline 90,73 Final 93,95	Baseline 84,48 Final 87,39
	Mean change within groups; [95% CI]; significance	3,23; [-1,78 to 8,23] p=0,19	2,90; [-2,00 to 7,80] p=0,24
	Difference between group mean outcomes; significance	0,32; p=0,93	
ZBI	Range of scores	Baseline 0 – 34 Final 0 – 35	Baseline 0 – 33 Final 0 – 34
	Mean score	Baseline 12,45 Final 14,91	Baseline 16,42 Final 15,71
	Mean change within groups; [95% CI]; significance	2,45; [0,66 to 4,25] p=0,01**	-0,71; [-2,89 to 1,47] p=0,51
	Difference between group mean outcomes; significance	3,16; p=0,03*	
SUM			
	Significance of the change within groups when comparing baseline to final mean assessment scores	**p=0,51**	**p=0,75**
	Significance of the difference between groups when comparing mean change in assessment scores	**p=0,44**	

Correlation analysis

The Pearson's product-moment correlation coefficients measure the strength of the linear dependence between two variables. If no linear relationship is found, the result is 0. A positive relationship would mean that both the scores changed in the same direction, i.e. both increased. A negative relationship would mean that the two scores changed in opposite directions, i.e. one increased and one decreased. The closer the correlation coefficient *r* is to ±1, the stronger the evidence of a linear relationship. Based on the significant results from the *t*-tests, the Pearson's correlations investigate linear relationships in the intervention and control groups.

The dyad QOL-AD scores are tested in both the intervention and control groups by comparing the person with dementia's rating with the caregiver rating. The results are interesting because in both groups, the person with dementia rates their quality of life higher but with more decline than the caregivers do. There are strong correlations between the individual with dementia's and the weighted QOL-AD mean change (*r*=0, 97 in control, *r*=0,93 in intervention), this is expected since the individual with dementia's score is the doubled score. In both of the groups, the individual with dementia and caregiver scores do not have a significant correlation (*r*=0,10, p=0,66 in control; *r*=0,24, p=0,19 in intervention), which indicates a low inter-rater agreement. This reveals that the caregivers in both groups perceived a lower quality of life but with less decline than the individuals with dementia did. The control group has non-significant decline in QOL-AD, and the intervention group shows significant decline.

The change in QOL-AD score reported by the person with dementia has significant, positive correlations with both ADL (*r*=0,44, p=0,01**) and IADL (*r*=0,39, p=0,03*) outcomes in the intervention group and there is a high probability that these variables are influencing quality of life for the person with dementia. This correlation has also been reported in previous research on QOL-AD and ADL/IADL [178]. It is interesting that that the person with dementia's self-reported QOL-AD score is highly correlated with assessments of their physical functioning, whereas the caregiver's and not even the weighted score show a significant correlation. The weighted QOL-AD outcomes do not have significant correlations with ADL or IADL in the intervention group and the control group results do not show significant correlations with QOL-AD and ADL or IADL.

Pearson's correlations are made to see if the IADL outcomes are correlated with SQLC and ZBI outcomes, both resulting in non-significant correlations in both groups. SQLC and ZBI are also found to have non-significant correlations in both groups [304]. Although IADL and ZBI both show significant changes in the control group, there is no evidence for a strong linear relationship [273]. Contrary to previous research, there is no evidence of strong correlations between declines in independent functioning and increases in caregiver burden; in both groups, IADL and ZBI to not have a significant correlation.

Summary of the analysis within groups

Both groups exhibit a significant decline in instrumental physical functioning (IADL), the intervention group shows a significant decline in QOL-AD, and there is a highly significant increase in the control group's caregiver burden (ZBI). The overall change was not significant in either the control or intervention group. The correlation analysis finds several significant results:

- QOL-AD score reported by the person with dementia is correlated with both ADL (p=0,01**) and IADL (p=0,03*) outcomes in the intervention group
- The QOL-AD scores reported by the individual with dementia and the caregiver do not have a strong correlation, indicating low inter-rater agreement in both the intervention and control groups
- Declines in IADL do not have strong correlations with declines in QOL-AD, SQLC, or ZBI

5.5 Subgroup analysis

This section discusses the subgroup analysis of the intervention and control groups. Participants were allocated to groups based on age, living status, caregiver relationship, and by caregiver burden outcomes. The independent *t*-tests are applied to test for significant differences between the groups in order to determine if there are influential variables in the assessment outcomes. The *t*-tests are run on all assessment results (MMSE, MoCA, ADL, IADL, QOL-AD, SQLC, and ZBI) as well as on length of use for the intervention group. The purpose of this analysis is to examine the data from another angle, to see if there are patterns within the subgroups, which could help identify confounding variables. It also provides a deeper analysis of the participants, and to help guide decisions on which subgroups would gain the most benefit from care interventions. Subgroup analyses are made for the following variables in this section:

- Cognition (grouped by higher and lower scores)
- Age (grouped by higher and lower ages)
- Living status (grouped by living alone or cohabitating)
- Caregiver relationship (grouped by spouse as caregiver, adult child as caregiver, or other as caregiver)
- Quality of life (grouped by positive and negative outcomes)
- Caregiver burden (grouped by positive and negative outcomes)

Outcomes by cognition

Higher and Lower MMSE scores

The control group has n=8 participants with maintained or improved MMSE and n=14 with declined MMSE. The paired *t*-tests show that those with positive effects in MMSE have significant decline in ZBI (mean 3,25; 95% CI [0,29 to 6.21]; p=0,04*). The control participants with negative effects in MMSE have a significant declines in MMSE (mean -1,86; 95% CI [-2,24 to -1,47]; p=0,0000001**), IADL (mean -0,50; 95% CI [-0,94 to -0,06]; p=0,03*), and QOL-AD (mean -2,52; 95% CI [-4,92 to -0,12]; p=0,04*), and a significant increase in SQLC (mean 4,50; 95% CI [0,14 to 8,86]; p=0,04*). The independent *t*-tests show the two control subgroups have significant differences in MMSE (p=0,00001**), QOL-AD (p=0,03*), and age of the person with dementia (p=0,05*), but that the outcomes between the two subgroups are not significantly different (p=0,62).

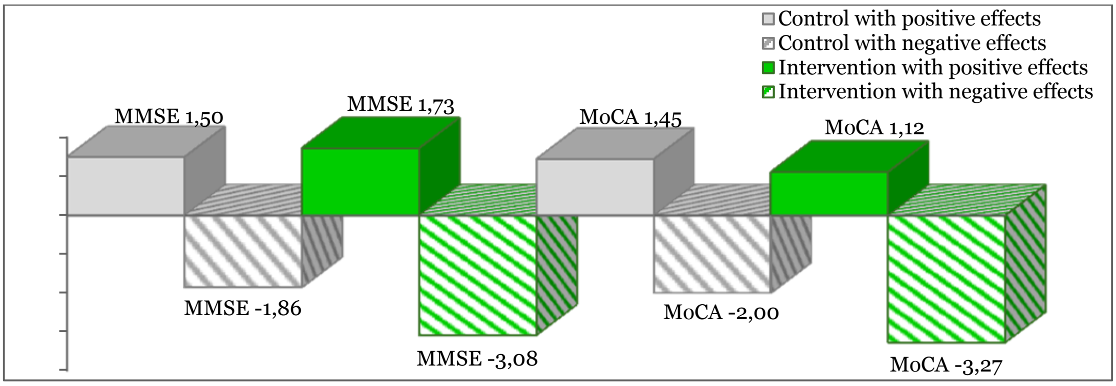
The intervention group has n=15 participants with positive outcomes in MMSE and n=13 with negative outcomes in MMSE. Paired *t*-tests reveal that the positive effects subgroup have a highly significant increase in MMSE (mean 1,73; 95%CI [0,35 to 3,11]; p=0,02**), and the negative effects subgroup have significant declines in MMSE (mean -3,08; 95% CI [-4,65 to -1,51]; p=0,001**) and MoCA (mean -2,00; 95% CI [-3,81 to -0,19]; p=0,03*). The independent *t*-tests show that the two intervention subgroups have highly significant differences in MMSE (p=0,00003**) and MoCA (p=0,02**), but the outcomes between the two subgroups are not significantly different (p=0,77).

Higher and Lower MoCA scores

The control group has n=11 participants with positive effects in MoCA and n=9 participants with negative effects in MoCA. The paired *t*-tests show that those with positive effects have significant negative effects in IADL (mean -0,82; 95% CI [-1,60 to -0,03]; p=0,04*) and ZBI (mean 3,27; 95% CI [0,44 to 6,11]; p=0,03*). The participants with negative effects in MoCA have a highly significant decline in MoCA (mean -2,00; 95% CI [-3,22 to -0,78]; p=0,01**). The independent *t*-tests show a highly significant difference in MoCA between the two control subgroups (p=0,002**), but the overall difference in outcomes between the groups is not significant (p=0,14).

The intervention group has n=17 with positive effects in MoCA and n=11 with negative effects in MoCA. The paired *t*-tests show that the positive effects subgroup has a highly significant increase in MoCA (mean 1,12; 95% CI [0,19 to 2,04]; p=0,02**). The negative effects subgroup shows a highly significant decline in MoCA (mean -3,27; 95% CI [-4,92 to -1,62]; p=0,001**) and a significant decline in QOL-AD (mean -2,79; 95% CI [-5,37 to -0,21]; p=0,04*). The independent t-tests show that there is a highly significant difference in MoCA outcomes between the intervention subgroups (p=0,00001**) but that the overall difference in outcomes is not significant (p=0,15). Figure 27 shows the mean outcomes in cognition scores for the participants.

Figure 27 Mean outcomes in cognition



Outcomes by age

Younger and Older participants with dementia

The control group, when dichotomized by the person with dementia's age (median age 81,5), has n=11 participants with dementia who are ≤81 years old (mean age 75,2), and n=11 who are >82 years old (mean age 86,1). The younger participants with dementia show a highly significant decline in quality of life (p=0,03*), and the older participants with dementia show a non-significant increase. The difference between QOL-AD in the two groups is highly significant at baseline and final evaluation, and also in the mean change (p=0,02**). Despite the younger control participants showing highly significant decline in IADL (p=0,02**), they have highly significantly higher ADL and IADL at both assessment points; however, the difference between the mean outcomes is not significant. While both subgroups show increases in ZBI, the younger group shows a highly significant increase (p=0,01**). A correlation test reveals that the younger control group's IADL and ZBI do not have a significant correlation (p=0,39). The mean change in the two control subgroups dichotomized by the person with dementia's age do not show a significant difference (p=0,25).

The intervention group adults with dementia (median age 75) has n=16 who are ≤75 (mean age 71,5) and n=15 who are ≥76 (mean age 83,5). In the intervention group, the older participants have a lower baseline mean QOL-AD, but show less decline, where the younger group has a highly significant decline in QOL-AD (p=0,01**). An independent *t*-test on the mean change between the two intervention subgroups reveals there is not a significant differences (p=0,31).

Younger and Older caregivers

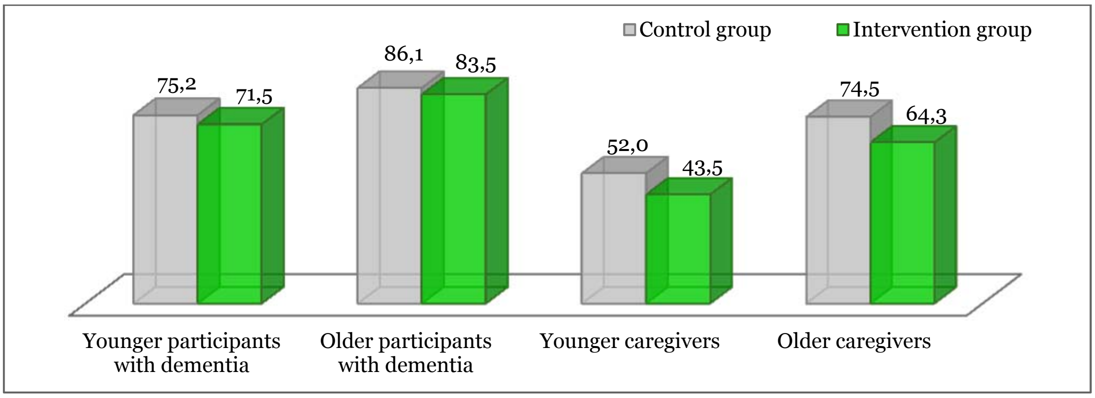
When the control group is dichotomized by caregiver age (median age 62,5), there are n=11 in each group. The younger (≤62) group of caregivers have a mean age of 52, and the older (≥63) caregivers have a mean age of 74,5. The independent *t*-tests find a significant difference between the two groups in QOL-AD outcomes (p=0,02**). The younger group shows decline (p=0,03*) and the older group shows non-significant increase. There are no other significant differences between the control subgroups. The mean change in the two control subgroups dichotomized by caregiver age do not show a significant difference (p=0,59).

When dichotomized by caregiver age (median age 55), there are n=13 intervention group caregivers ≤54 (mean age 43,5) and n=14 caregivers ≥55 (mean age 64,3). Within the younger subgroup, there is a significant decline in QOL-AD (p=0,02**), while the older subgroup shows a non-significant decline. The mean change in the two intervention subgroups dichotomized by caregiver age do not show a significant difference (p=0,27).

Within all of the younger subgroups, there were significant decreases in quality of life, and the older control subgroups both show increases in quality of life. The younger control group shows a highly significant decline in IADL and highly significant increase in ZBI. The intervention groups both show declines in QOL-AD, and both of the younger subgroup shows highly significant decline. In the control groups, there are highly significant differences between the ages of both of the younger and older subgroups, whereas there are no significant differences in age between the intervention groups.

Figure 28 shows the mean ages of the control and intervention participants at baseline evaluation.

Figure 28 Mean ages in the groups



Outcomes by living status

The control group is dichotomized by adults with dementia who live alone (n=7) and those who cohabitate (n=15). The paired *t*-tests within each group show no significant differences in the assessments. The independent *t*-tests on the control group, shown in Table 16, shows a significant difference (p=0,03*) in caregiver age between the two groups. This is most likely due to the cohabitating caregivers largely being spouses, who will typically be older, and this is supported by the data (n=12 of those who cohabitate, have their spouse as caregiver). The independent *t*-tests also show a highly significant difference between final QOL-AD scores (p=0,02**) but not in mean outcomes. The control participants who live alone have lower scores at both assessments, and show more decline than the participants who cohabitate. Although neither of the control subgroups show significant declines in QOL-AD, the participants who cohabitate with their caregivers show that their QOL-AD scores are higher and more stable. Aside from the difference in QOL-AD outcomes, the control group shows no other significant between-group differences.

The same dichotomization is done for the intervention group, where n=15 live alone and n=16 cohabitate. The paired *t*-tests within each group show that there are significant differences within the groups living alone and cohabitating, shown in Table 16. There is a highly significant decline in the IADL of participants living alone (p=0,02**, mean decline=-1,07), even though they have significantly higher baseline ADL and (highly) significantly higher IADL scores. It is not surprising that those who live independently alone exhibit higher physical and independent functioning. The caregivers for the individuals who live alone also have (highly) significantly higher SQLC and lower ZBI scores at both assessment intervals. It could be expected that caregivers who do not live with the person with dementia will have higher scores in their quality of life and lower levels of burden, due to fewer care tasks and psychological strain. Although there are several highly significant differences between the subgroups at each assessment, there are no significant differences between the score outcomes.

There is an unexplained highly significant difference in the length of using the technology, with those who live alone using the telecare system over 3 months longer than those who cohabitate. One explanation could be that since the majority of the service training took place when both the person with dementia and caregiver could be present; this could have delayed installations in the shared homes. The difference could be due to the time that participants joined the study and received the installations, which was delayed in some regions due to the European economic crisis in 2009. Another explanation could be that individuals with dementia who live alone may be more likely to seek out formal support services, as those who cohabitate have a caregiver in the home who provides support. Table 16 shows the significant results within the groups when separated by living arrangement.

Table 16 Significant differences between intervention participants who cohabitate and who live alone

Variable	Independent *t*-test result	Alone group mean score (MAD) [95% CI]	Cohabitating group mean score (MAD) [95% CI]
CONTROL GROUP		**n=7**	**n=15**
Final QOL-AD	p=0,02**	29,05 (5,67) [23,60 to 34,50]	34,07 (1,67) [32,29 to 35,84]
Caregiver age	p=0,03*	53,7 (2) [45,98 to 61,45]	67,7 (14) [59,86 to 75,47]
INTERVENTION GROUP		**n=15**	**n=16**
Baseline ADL	p=0,04*	5,73 (0) [5,48 to 5,99]	4,81 (1) [3,98 to 5,64]
Baseline IADL	p=0,001**	5,40 (1) [4,52 to 6,28]	3,44 (1) [2,82 to 4,05]
Baseline SQLC	p=0,001**	96,20 (12) [89,73 to 103,67]	73,50 (13) [62,97 to 84,03]
Final SQLC	p=0,01**	98,07 (8) [90,47 to 105,66]	77,38 (18,50) [64,37 to 90,38]
Baseline ZBI	p=0,0002**	10,80 (3) [7,32 to 14,28]	21,69 (4) [17,67 to 25,71]
Final ZBI	p=0,01**	11,40 (5) [7,04 to 15,76]	19,75 (4,5) [15,20 to 24,30]
Length of use of services	p=0,001**	245.00 (41) [204,44 to 285,56]	143,19 (67,50) [99,07 to 187,30]

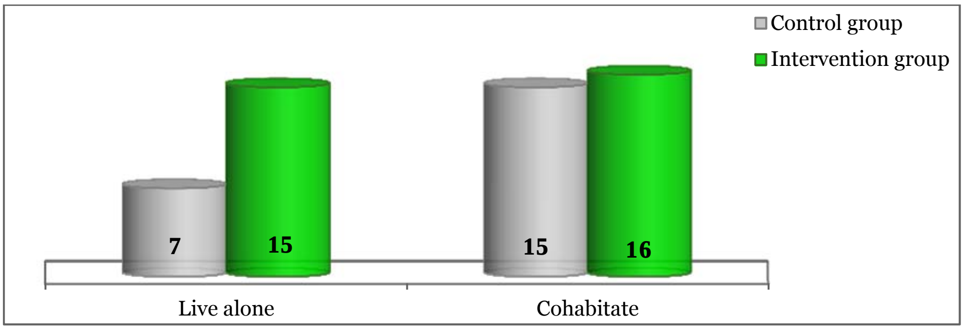
Living alone

The control participants living alone have caregivers who are significantly older than those who cohabitate. They also have lower QOL-AD scores and show more (non-significant) decline. The intervention participants who live alone have highly significantly higher IADL and significantly higher ADL, although they show highly significant declines in IADL. The intervention caregivers of those who live alone show highly significantly better SQLC and ZBI scores than the caregivers of the cohabitating subgroup. The results indicate that the intervention participants who live alone have higher independent functioning, and their caregivers have higher quality of life and less caregiver burden. This is consistent with the previous research on caregivers who live with the person they provide care for.

Cohabitating

The control participants who cohabitate have caregivers who are significantly younger than those who live alone, and they have higher QOL-AD scores that also show little change. This could suggest that they experience more stability in their home and daily lives. The intervention participants who cohabitate have highly significantly lower ADL and IADL scores, and their caregivers have highly significantly worse SQLC and ZBI scores. These participants also used the technology for a highly significant shorter amount of time than the intervention subgroup who lives alone. Figure 29 shows the number of participants who live alone and who cohabitate in the control and intervention groups.

Figure 29 Living arrangement of the participants with dementia, by number



Outcomes by caregiver relationship

The control group is separated by their caregiver role, with n=11 in each subgroup of spouses and children. In the spouses subgroup, the MMSE score has a significant decline (p=0,05*) and the SQLC score has a significant improvement (p=0,04*). The subgroup of adult children as the caregiver shows significant decline in IADL (p=0,05*) and a highly significant increase in ZBI (p=0,01**). The subgroup's highly significant increase in caregiver burden could be explained by the significant decline in IADL, and will be examined further in a correlation test. It is interesting that the adult children also show a (non-significant) increase in the caregiver's quality of life, despite such an increase in caregiver burden. The independent *t*-tests show a highly significant difference in the final QOL-AD scores (p=0,02**) between the spouses subgroup (mean 34,76) and the children subgroup (mean 30,18).

When the intervention group is separated by caregiver role, there are three groups: n=15 children who are caregivers, n=9 spouses who are caregivers, and n=5 who classify themselves as other. The paired *t*-tests within each of the subgroups reveal few significant changes. The group who have children caregivers show a significant decline in IADL (p=0,03*). The caregivers classified as other show a highly significant improvement in ZBI (p=0,02**). The subgroup who have spouses as caregivers do not show any significant within-group differences. Table 17 presents the significant results between the intervention group's 3 types of caregivers.

Table 17 Significant differences between the intervention participants when separated by caregiver relationship

Subgroups tested by independent *t*-test	Baseline MMSE	Baseline MoCA	Final MoCA	Baseline IADL	Final IADL	Final QOL-AD	Caregiver Age
Child and Spouse	0,03*	0,001**	0,001**	0,17	0,73	0,55	0,0002**
Child and Other	0,28	0,64	0,70	0,09	0,01**	0,02**	0,34
Spouse and Other	0,45	0,01**	0,02**	0,003**	0,01**	0,29	0,01**

There are several significant differences between the three subgroups, shown by the independent *t*-tests in Table 17. Only the variables that are significantly different are shown, the other results are non-significant differences. The intervention group participants who have spouses as caregivers show the highest overall cognitive scores, and those who have adult children as caregivers show the lowest overall cognitive scores. This explains the significant difference between the baseline MMSE scores and the highly significant difference in MoCA scores. The participants who have spouses as caregivers have the lowest mean independent functioning at baseline, but show very little statistical difference between intervals (p=1,00). The subgroup of children as caregivers are the only subgroup to have significant decline in their IADL (p=0,03*), while the subgroup of others has the highest lowest IADL scores, thus explaining the significant difference between spouses and others. The subgroup with children as caregivers shows the lowest quality of life scores (both QOL-AD and SQLC). Both subgroups of children and spouses show declines in QOL-AD, while the participants with others as caregivers show a non-significant increase. This explains the significant difference between the subgroups with lowest and highest means on QOL-AD. The subgroup of others also shows highly significant improvement in their caregiver burden (p=0,02**). The spouses are significantly older than the other two subgroups, who show similar ages. As could be expected, the caregivers who are adult children and those who are spouses would have significantly different ages. Although, of the n=7 caregivers who were classified as other, only 4 gave their age, so the data is too small to make assumptions about.

Spouse

The control subgroup who have spouses as caregivers show a significant decline in MMSE and a significant improvement in SQLC. The control spouse has a highly significantly higher final QOL-AD score when compared to the adult children subgroup. The intervention subgroup of spouse caregivers has higher ZBI scores, but show (non-significant) improvement, whereas the control subgroup shows (non-significant) decline. Both subgroups with spouses as caregivers show (non-significant) declines in QOL-AD. In both the control and intervention groups, the subgroup with spouses show the highest overall cognition scores.

Adult child

Both of the control and intervention subgroups with adult children as caregivers show significant declines in IADL, (non-significant) declines in QOL-AD, and (non-significant) increases in SQLC. In the total participant sample, those who have adult children as the caregiver show the lowest quality of life scores (both QOL-AD and SQLC – except baseline SQLC in the control group). In both the control and intervention groups, the subgroup with adult children show the lowest overall cognition scores. The main difference between the intervention and control subgroups who have adult children as caregivers is that the control subgroup shows highly significant increases in ZBI while the intervention subgroup shows non-significant increases in ZBI.

Other

The intervention subgroup with others as the caregiver show (non-significant) improvement in quality of life (both QOL-AD and SQLC), and a highly significant improvement in ZBI. They also presented the highest ADL and IADL scores of the intervention group. The control group did not have any caregivers classified as other.

Outcomes by effect in quality of life

The control and intervention groups did not have significant differences between their QOL-AD and SQLC outcomes. Further tests investigate if there are any associations or correlations within the subgroups ‘ quality of life outcomes. The results show that there are not significant differences between subgroups who show positive and negative improvement.

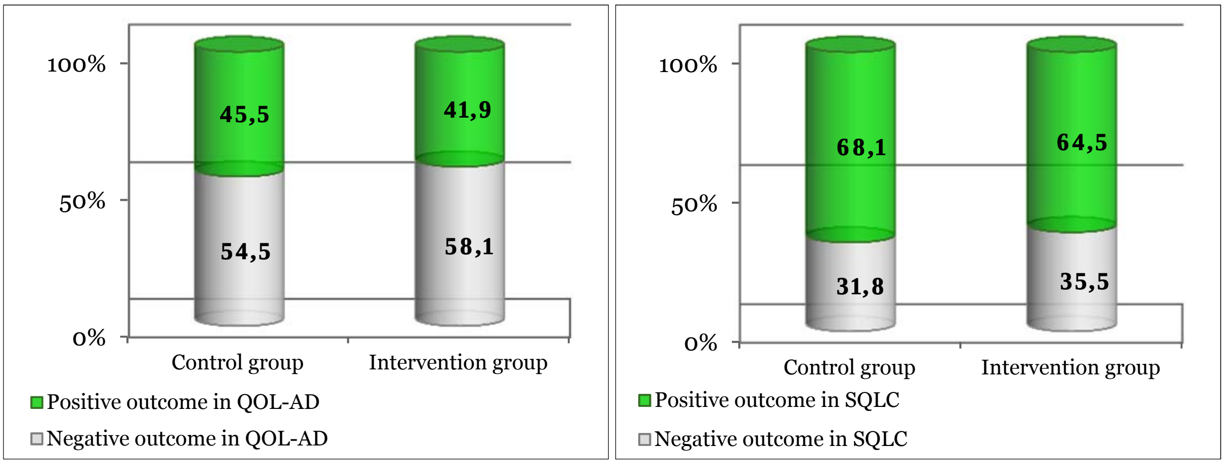
Quality of life of the person with dementia

The control group split by improvement in QOL-AD (n=10) and decline in QOL-AD (n=12) show non-significant difference between the mean outcomes (p=0,90), and only show a significant difference between QOL-AD outcomes. In those who improved, there is a significant correlation with increase ZBI score (*r*=0,84, p=0,002**). The control group with declines in quality of life of the person with dementia did not have any significant correlations with QOL-AD.

The intervention group has n=13 with improvement in QOL-AD and n=18 with declines in QOL-AD. The difference between the two subgroups' mean outcomes is non-significant (p=0,95) and the only significant difference between them is in QOL-AD outcome. In the subgroup with improvement, QOL-AD has strong linear correlations with ADL decline (*r*=-0,71, p=0,02**) and SQLC improvement (*r*=0,58, p=0,04*). The intervention subgroup who shows decline also shows significant correlations with ADL declines (*r*=0,58, p=0,01**) and IADL declines (*r*=0,60, p=0,01**).

As the weighted score is considered a valid portrayal of QOL-AD [212] [305], this suggests that declines in independent functioning and quality of life for the person with dementia have a strong linear correlation in the intervention group participants. Figure 30 shows the proportion positive and negative outcomes in quality of life for the participants in each group.

Figure 30 Outcomes in quality of life, by percentage



Quality of life of the caregiver

In the control group, n=15 improved SQLC score and n=7 has declines. The two groups show significant differences between SQLC (p=0,003**), the ages of the person with dementia (p=0,03*), and caregiver ages (p=0,005**); however, the difference between the mean outcomes in the control subgroups is non-significant (p=0,77). Those who show improvement do not have any significant correlations within the outcomes, and those who have declines in SQLC show significant correlations between SQLC outcomes and IADL (*r*=-0,89, p=0,01**), MMSE (*r*=0,-0,82, p=0,02**), and ZBI (*r*=-0,83, p=0,02**).

In the intervention group, n=11 shows decline in SQLC, and this is found to be significantly correlated with their decline in MoCA scores (*r*=0,65, p=0,03*). There are n=20 who show improvement in SQLC, and the improvement is not strongly correlated with any other variable, Between the intervention subgroups, there are significant differences between MMSE (p=0,003**), IADL (p=0,04*), SQLC (as expected), and ZBI outcomes (p=0,05*), and in length of use (p=0,04*); however the difference in outcomes between the intervention sub-groups is non-significant at p=0,86. A discussion on the quality of life results for the caregivers is given in Paper H

Outcomes by effect in burden

The independent *t*-tests show no significant differences in the baseline and final assessment scores between the intervention and control groups. The only significant difference is between the ZBI score changes. The intervention group ZBI score improved by a total of 22 points (4,3%) while it declined by a total of 54 points(19,7%) in the control group. To test ZBI further, the caregivers are dichotomized by positive effects in burden (≤0) and negative effects in burden (>0) to explore if other assessment outcomes are associated with ZBI change. The independent *t*-tests first look for differences between the positive and negative effects groups, and the paired *t*-tests will tell if there are outcomes within the groups that influence the difference between the groups. The independent *t*-tests show a significant difference in ZBI outcomes, and the paired *t*-tests find this is due to a highly significant decline in the control group's ZBI. The *t*-test results on caregiver burden are given in Table 18.

Table 18 Results of the *t*-tests between the dichotomized ZBI score changes [273]

	Positive effect on ZBI (≤0)	**Negative effect on ZBI (>0)**	**Independent *t*-test on IADL between groups**	**Paired *t*-test on IADL within groups [95% CI]**
Control (n=22)	(n=7) 31,8%	(n=15) 68,2%	0,009**	p=0,004** in negative effects group [-1,42 to -0,32]
Intervention incl. DK (n=31)	(n=20) 64,5%	(n=11) 35,5%	p=0,40	p=0,04* in negative effects group [-1,78 to -0,04]
Intervention excl. DK (n=25)	(n=16) 64%	(n=9) 36%	p=0,45	p=0,04* in negative effects group [-2,16 to -0,06]
All participants incl. DK (n=53)	(n=27) 50,9%	(n=26) 49,1%	p=0,08	p=0,0004** in negative effects group [-1,33 to -0,44]
All participants excl. DK (n=47)	(n=23) 48,9%	(n=24) 51,6%	p=0,11	p=0,0004** in negative effects group [-1,43 to -0,48]

The younger caregivers and the children caregivers subgroups both show significant declines in IADL and significant increases in ZBI, indicating possible correlations between age, IADL, and ZBI. Both the control and intervention groups have significant declines in IADL, and the subgroups who show decline in ZBI also show significant declines in IADL. This relationship between IADL and ZBI is examined further for both groups, divided by ZBI outcomes, presented in Table 19. In the intervention group, declining ADL and IADL scores are correlated with declining QOL-AD scores, exhibiting strong, positive linear relationships and a high probability of physical and independent functioning influencing declines in the person with dementia's quality of life.

Table 19 Significant correlations when divided by ZBI outcomes, n=53

	Correlated domains in the control group	Correlated domains in the intervention group
Improved ZBI **Control n=7** **Intervention n=20**	SQLC improvement and caregiver age (*r*=0,80, p=0,03*)	• MMSE and MoCA declines (*r*=0,61, p=0,004**) • MMSE decline and SQLC improvement (*r*=-0,59, p=0,01**) • MoCA decline and SQLC improvement (*r*=-0,73, p=0,003**) • MoCA and ADL declines (*r*=-0,51, p=0,02**) • ADL and IADL declines (*r*=0,67, p=0,001**) • ADL and QOL-AD declines (*r*=0,44, p=0,05*)
Declined ZBI **Control n=15** **Intervention n=11**	IADL decline and SQLC improvement (*r* =-0,53, p=0,04*)	• ADL decline and caregiver age (*r*=-0,73, p=0,01**) • SQLC improvement and caregiver age (*r*=-0,61, p=0,05*)

The only significant difference found from the tests on IADL outcomes, was between the control subgroups. For both the control group and intervention group, the subgroups who have negative effects in burden show significant declines in IADL. While all the negative ZBI subgroups show significant decline in IADL, only the control group shows that this difference is significant between the subgroups. In the intervention group, the significant declines in IADL are still not significantly different from the IADL in the positive effects subgroup; however, this is likely due to the lower overall IADL scores in the intervention group. The intervention group (incl. DK) shows highly significant improvement in ZBI (p=0,0001**) while the control group with positive results in ZBI shows non-significant improvement. Previous research shows that significant declines in physical functioning are associated with increases in caregiver burden, and it will be investigated if this is also the case in this study. The intervention participants also show a significant difference from each other in the length of using the services. Interestingly, the group who show negative effects in caregiver burden used the technology for a mean longer time. A further discussion on the outcomes in caregiver burden is offered in Paper G.

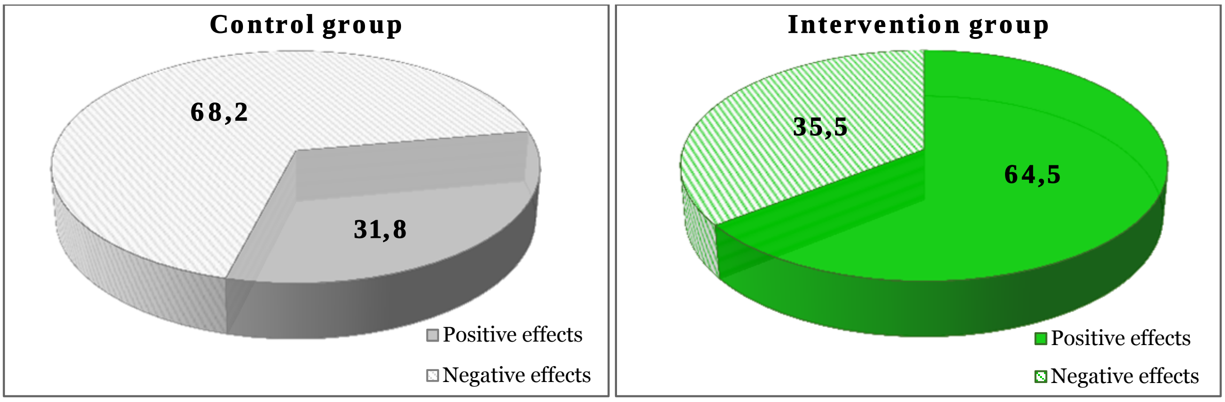
Positive effects

Of the participants who have improvement in caregiver burden, both the control and intervention groups show non-significant improvement in IADL. The intervention subgroup shows a highly significant improvement in ZBI while the control group shows non-significant improvement.

Negative effects

Of the participants who have increases in caregiver burden, both the control and intervention groups show significant declines in IADL. However, the control subgroup shows a highly significant decline in IADL, and it is highly significantly lower than in its counter subgroup. The intervention subgroup with negative outcomes in ZBI used the intervention for a significantly longer time than the subgroup with positive outcomes. Figure 31 shows the proportion of participants with positive and negative outcomes in caregiver burden.

Figure 31 Outcomes in caregiver burden (ZBI), by percentage



Subgroup analysis summary

In both the control and intervention groups, the older caregivers provide care to older individuals with dementia. The control subgroups who are older have higher scores on QOL-AD and show a non-significant increase. The difference in QOL-AD outcomes between the older and younger control groups is significant (highly significant when dichotomized by the person with dementia's age). Being younger is associated with significant declines in IADL, QOL-AD, and ZBI. Regardless of the younger control participants showing highly significant decline in IADL, they have higher ADL and IADL, and to a highly significant degree. The younger intervention subgroup also shows significant declines in IADL, and all intervention subgroups except for the older caregivers, show (non-significant) improvement in ZBI. However, the independent *t*-tests on the intervention groups show no significant differences between the groups, indicating that age is not a confounding variable for the intervention group.

The control participants who live alone have lower QOL-AD scores at both assessments, and show decline when compared to those who cohabitate, though neither of the control subgroups show significant declines in QOL-AD. The intervention participants who cohabitate are younger and show (non-significantly) higher cognitive scores. The participants who live alone and have others as caregivers both have the highest independent functioning and have the highest quality of life scores (both QOL-AD and SQLC). The intervention group results indicate that there are associations with older age, living alone, and having higher independent functioning, which influence higher overall quality of life. However, the results from the control group show that the participants who cohabitate with their caregivers are younger, show less decline in independent functioning, and have higher and more unvarying QOL-AD scores, suggesting more stability in their home environment and daily lives.

In the control subgroup with spouses as the caregiver, there is a significant increase in caregiver quality of life and (non-significantly) higher QOL-AD, even though the MMSE score has significant decline. Having an adult child for a caregiver in the control group is associated with significant declines in IADL and highly significant increases in ZBI. The intervention subgroup with others as caregivers, where the majority live alone, is the only of all of the intervention subgroups to show (non-significant) increases in QOL-AD (the control subgroups who are older both show non-significant increases in QOL-AD as well). In the intervention group, having a spouse as a caregiver is associated with significantly higher scoring on cognitive assessments, particularly on assessments sensitive to milder cognitive changes, despite this subgroup having the lowest independent functioning. Comparably, the participants who have adult children as caregivers have significantly lower cognitive assessment scores. The intervention group results show that both having a spouse as a caregiver and cohabitating with the caregiver is related to higher cognitive scores and less decline, particularly in milder declines (i.e. MoCA scores).

The control group shows a highly significant increase in caregiver burden while the intervention group shows non-significant improvement. In comparing the caregivers who have positive effects in caregiver burden with those who have negative effects in burden, there is a highly significant difference between the IADL scores of the control group. For all the participants who have negative effects in caregiver burden, there is a significant association with declines in independent functioning. It is reasoned that the significant declines in physical functioning are associated with increases in caregiver burden, but the results do not indicate strong linera relationships.

5.6 Analysis of gerontechnology use outcomes

From the previous analysis on the intervention group, significant declines in IADL and QOL-AD are found to be correlated with high significance. It is furthermore shown that the intervention group does not have a significant decline in ZBI as the control group has, indicating possible protective effects of using gerontechnology to prevent an increase in caregiver burden. This section expands on the data on the use of the gerontechnology services by the intervention group.

Outcomes based on the length of use

The descriptive statistics on the type, function, percentage of use, and length of use are presented in Table 20. The intervention group is dichotomized by length of use to test if longer use is associated with positive differences. First, *t*-tests are made within and between the dichotomized groups to identify significant differences, then Pearson correlations look for linear relationships between the length of use and outcomes.

Table 20 Descriptive statistics on the use of the telecare services by the intervention group

Type of service	Functions of the service	Percentage of use (n=31, incl. DK)	Mean length of use (days)
Increased contact	Contact button on the Carebox touchscreen for the older adult	71%, n=22	198
Reminders	Reminder for date, time, meals, medication, appointments, etc.	67,7%, n=21	209
Multimedia for cognition	Memory stimulation with digital photos (reminiscence)	54,8%, n=17	210
	Training for mental ability and performance (brain games)	41,9%, n=13	173
Intelligent front door	The service monitors door use and caregivers are notified if the person is leaving the home or has been gone too long	41,9%, n=13	227
Home safety	Stove and oven monitor (temperature sensor, use monitor, and actuator for automatic shut-off), reminds the person to turn off the appliance and generates alarms to caregivers if necessary	41,9%, n=13	229
	Smoke detector and fire alarm to authorities in an emergency	54,8%, n=17	225
	Reminder if the water is left running (kitchen and bathroom)	3,2%, n=1	412
Sleeping sensor	Senses how long they have been in bed and if they are leaving the bed at night (frequency and length)	35,5%, n=11	199
Medication assistant	Medicine reminders communicated through the Carebox, alert is generated if the reminder is ignored	29%, n=9	293
Outdoor safety	GPS device for the location of the person outdoors	41,9%, n=13	190
	Panic button with GPS tracker if the person becomes lost	19,4%, n=6	145
	GPS device with a fall alarm to caregivers if a fall is detected	9,7%, n=3	144

To look deeper into the relationship between technology use and quality of life, the length of technology use is dichotomized into groups of longer and shorter use. The median length of use is 203 days, and n=16 used the services 203 days or less and n=15 used the services 204 days or more. *T*-tests are made to test between the groups. Table 21 shows the descriptive statistics on the services by dichotomized length.

Table 21 Summary of the telecare services used by the dichotomized intervention group (incl. DK, n=31)

	≤203 days, n=16	≥204 days, n=15	Total, n=31
Mean	120,69	269	192,45
Standard Error	14,85	12,89	16,66
Median	122	267	203
Mode	203	N/A	203
Standard Deviation	59,41	49,94	92,76
Sample Variance	3528,89	2494,43	8605,06
Kurtosis	-0,88	4,27	-0,31
Skewness	-0,11	1,71	-0,01
Range	187	208	396
Minimum	16	204	16
Maximum	203	412	412
Sum	1931	4035	5966
95% Confidence Level	31,65	27,66	34,03

Independent *t*-tests compared the score differences between the two groups of length of use (i.e. shorter use against longer use). This investigated the probability that longer use would provoke better outcomes. The results in Table 22 show that the length of use has a significant association with caregiver quality of life (SQLC).

Table 22 Results of the *t*-tests on the intervention group score changes and length of use (incl. DK, n=31)

Outcome tool	Significance of the difference between groups	Mean change within groups
MMSE	p=0,40	Short use group declined (-1,07) Long use group improved (0,07)
MoCA	p=0,85	Short use group declined (-0,71) Long use group declined (-0,50)
ADL	p=0,90	Short use group declined (-0,31) Long use group declined (-0,27)
IADL	p=0,78	Short use group declined (-0,50) Long use group declined (-0,67)
QOL-AD	p=0,18	Short use group declined (-0,71) Long use group declined (-2,88)
SQLC	p=0,05*	Short use group improved (7,38, p=0,04*) Long use group declined (-1,87)
ZBI	p=0,83	Short use group improved (-0,94) Long use group improved (-0,47)
All	**p=0,28**	

The analysis on the outcomes based on length of using the services shows that there is a highly significant difference in caregiver quality of life: those who used the technology less than 204 days had significant improvement in their SQLC, influencing a significant difference between the two groups. Overall, the difference in the outcomes between the groups is non-significant. A Pearson's correlation finds significant linear relationships in both groups. In the group who used the intervention 203 days or less, a highly significant, positive relationship is found between basic (ADL) and instrumental (IADL) activities of daily living, (*r*=0,68; p=0,004**), and a significant negative correlation between length of use and ADL (*r*=-0,50; p=0,05*). The group who used the intervention 204 days or more show highly significant, negative relationships between length of use and IADL (*r*=-0,60; p=0,02**), length of use and SQLC (*r*=-0,65; p=0,01**), and a significant negative relationship between IADL and ZBI (*r*=-0,53; p=0,04*) and QOL-AD and ZBI (*r*=-0,51; p=0,05*).

Outcomes based on non-standardized questionnaires

In the evaluation of user acceptance and satisfaction with the ISISEMD telecare system, the project partners used explorative questions on global domains relating to quality of life [272]. The results are presented in Table 23. This comparison is to show the outcomes between the quantitative evaluations and the qualitative evaluations as another angle on the quality of life of the participants. Out of 62 participants (31 older adults and 31 caregivers), 61 responded to the question regarding the older adult's quality of life and 55 responded regarding the caregiver's quality of life (the adults with dementia in Denmark did not answer this question about their caregiver's quality of life). Only the caregivers were asked the question about care responsibilities, and one did not answer. All other questions had 61 responses [272] [281].

Table 23 Intervention group outcomes from the standardized assessments and additional questionnaires, incl. DK n=62

Variable	Standardized questionnaire results (n=31, mean change)	Additional questionnaire results (n=61)
Quality of life of the adult with dementia	QOL-AD 41,9% show positive effects (2,32) 58,1% show negative effects (-4,70) Paired *t*-test shows significant decline (-1,76, p=0,04*)	62,9% report increase 37,1% report maintenance 0% report decrease
Quality of life of the caregiver	SQLC 64,5% show positive effects (9,85) 35,5% show negative effects (-9,73) Paired *t*-test shows non-significant improvement (2,90, p=0,24)	70,9% report increase 19,4% report maintenance 0% report decrease
Independent living	ADL 80,7% show positive effects (0,12) 19,4% show negative effects (-2,00) Paired *t*-test shows non-significant decline (-0,29, p=0,13) IADL 61,3% show positive effects (0,47) 38,7% show negative effects (-2,25) Paired *t*-test shows significant decline (-0,58, p=0,05*)	61,3% report increase 37,1% report maintenance 0% report decrease
Change in care responsibilities	ZBI 64,5% show positive effects (-3,95) 35,5% show negative effects (5,18) Paired *t*-test shows non-significant improvement (-0,71, p=0,51)	61,3% report decrease 35,5% report maintenance 0% report increase
Safety in the home environment		80,6% report increased safety 19,4% report maintained safety 0% feeling less safe
Satisfaction with the telecare system		88,7% report satisfaction 11,3% report dissatisfaction 1,6% report disappointment

While nearly half of the QOL-AD scores show there were positive effects, the larger percentage of participants show greater negative effects, and the overall QOL-AD outcomes shows a significant decline. However, none of the individuals with dementia and their caregivers reported that they felt the quality of life of the adult with dementia declined, and over 72% reported improvements in the global questions. There were nearly twice as many caregivers who had positive effects in their SQLC than those who had negative effects, although the paired *t*-test shows a non-significant difference. All of the participants who responded feel that the quality of life of the caregiver had positive effects, with over 70% reporting increases. The majority of the participants show positive effects in their physical and independent functioning, but these effects are outweighed by the overall negative effects in the ADL and IADL scores. In comparison, the majority of the participants report that they felt independent living increased for the person with dementia and no one reported declines in independent living. Almost 65% of the caregivers show positive effects in their ZBI, and that corresponds with almost 62% reporting decreases in their care responsibilities. However, the 35,5% who show negative effects in ZBI corresponds with the same percentage of those who report maintained care responsibilities, while none of the caregivers reported increases in their care responsibilities. All of the participants report either maintained or enhanced safety in the home environment and nearly 90% report satisfaction with using the system.

While the responses may bring more questions than answers, they are representing the phenomenological perspective of the end users in their interaction with the telecare system. The variation in outcomes between the standardized assessments and the additional questions could be explained by the questions themselves. It could be that the non-standardized questionnaires were not valid to assess the domains (i.e. care responsibilities has a different meaning than caregiver burden), and it could be that the standardized assessments miss some valuable domains that were affected by the intervention. The standardized assessments asked closed questions on specific, defined domains, whereas the global perception of the domains allows the participant to include other factors that influence the overall quality of life. Another possibility could be that the standardized tools are better at detecting declines. All participants will have different personalities and outlooks that shape what they perceive to be improvement, maintenance, and decline, and will have differing levels of insight into the situation, which will affect how they respond. An interesting aspect of these outcomes is that the responses were recorded at the same interview and participants answered questions on the standardized assessments before being asked about their global perceptions. It is recognized that there is some disconnect between defined and global responses, and that this could be due to lack of insight among the participants. As an example of this, the participant who reports the highest increase in ZBI (17 points), also responds that the intervention has increased quality of life in the dyad and that the technology has helped to decrease care responsibilities.

Intervention group participants were asked about their willingness to use and pay for services like the ones in the project [272] [281]. 48,4% of caregivers and 35,5% of adults with dementia definitely would use a system like this, and another 41,9% of caregivers and 54,8% of adults with dementia would consider using a system like this. In total, 90,3% of the intervention group reports a willingness to use services like these, and 9,7% report that they are not willing to use a system like ISISEMD. In total, 53,2% of participants report willingness to pay for services like the ones offered; 58,1% of the adults with dementia and 48,4% of the caregivers are willing to pay for these services (12,9% did not answer). The ISISEMD project reports that if the participants were consumers, the total cost of the system (for all services) is €3.470 per user and €60.000 for the regional care service providers [306]. Despite the direct costs to the stakeholders, there are additional values when compared to traditional dementia care services (e.g. the control group). The regional care providers can benefit from telecare through increased efficiency in information collection and processing, improved billing processes, increased management capacity, more convenience, faster accessibility, and resource savings for medical and care professionals. Based on the average cost to receive formal care in the regions, e.g. the potential annual savings per person from using a home telecare system, Table 24 shows the willingness to pay and the average costs of formal care [272].

Table 24 Potential regional savings in the annual costs of formal care for one person

	DENMARK (n=6 dyads)	**NORTH IRELAND (n=7 dyads)**	**GREECE (n=10 dyads)**	**FINLAND (n=8 dyads)**
Mean length of use	215 days	160 days	137 days	273 days
Participants willingness to use	100% of adults with dementia 100% of caregivers	71,4% of adults with dementia 57,1% of caregivers	90% of adults with dementia 100% of caregivers	100% of adults with dementia 100% of caregivers
Participants willingness to pay	66,7% of adults with dementia 0% of caregivers (16,7% did not answer)	57,1% of adults with dementia (14,3%¤ did not answer) 42,9% of caregivers (14,3%¤ did not answer)	50% of adults with dementia 70% of caregivers	62,5% of adults with dementia 62,5% of caregivers (12,5% did not answer)
Annual amount participants are willing to pay	€135-940 for the equipment	€12-408	€1.200-3.600	€360-1.200
Annual costs of formal care	€48.000 for nursing home placement	€23.676 for nursing home placement	€15.600-20.400 for hospitalization €8.400-9.600 for formal care in the home	€36.000 for dementia care home placement

Outcomes based on qualitative information

The qualitative information presented here serves to provide another angle of looking at the research. Ultimately, it is hoped that other dementia intervention programs can benefit from lessons learned in the ISISEMD project. More information on the qualitative outcomes from the project can be found in Papers D, E, G, and in ISISEMD project reports [272].

The reliability of the platform and availability of the service were some of the most crucial requirements of the telecare. The telecare system had some instability, especially in the beginning of the testing. The number of visits to the participants' homes was more than expected, largely due to technical issues and training. Many of the issues were with the surrounding technical infrastructure (i.e. operating systems and ADSL connectivity). A high number of initial false alarms can have negative effects by disrupting the caregivers, unnecessarily causing concern, and some participants with dementia also expressed concern over their caregivers having "false scares." Of those who found the instability bothersome but remained in the trial, many understood that the project was developing and testing the services and knew some problems were to be expected. As one of the most crucial requirements is the reliability of the system, the conclusion is that the small-scale testing of the technologies should have been longer to ensure a reliable system before starting real-life testing. The system's stability issues mean that during the testing period, the system was still being optimized. This not only can influence the outcomes in quality of life due to overcoming technical difficulties, but there are ethical concerns with testing unstable services in the homes of individuals with dementia. Furthermore, with installation difficulties and delays in service availability, credibility can become an issue for the end users.

One element of the research that is not given as much attention is the outcomes for the professional caregivers. They are the primary local contact points for the participants to the project. The formal caregivers had significant roles in the evaluation administration, and found the questionnaires were difficult to understand and required them to become familiar with research skills and methods. They emphasized keeping the number of assessment tests as limited as possible, since it is taxing on the participants to answer so many in one interview. The professional caregivers also expressed concern over the appropriateness of the assessments, ZBI in particular, and felt that it was an ethically gray area if the wording could provoke poorer opinions on quality of life. They acknowledge that technical skills are increasingly important in elder care, but found acquiring the new skills challenging. The professional caregivers also conducted the majority of the training for the participants. They needed the skills to use the internet to access the telehealth portal, to adjust the services, and to explain the functions to the participants. Their feedback and collaboration directly helps to improve the system. The formal caregivers did not need to understand all technical aspects, as the regions had local IT support to handle problems. The regions report increased awareness and knowledge of eHealth and smart homes, solutions in elderly care, and how other countries provide elder care.

For the individuals with dementia, it is challenging for them to use technologies they have never previously used, thus the interactive services were more difficult for them to access than the non-interactive services. The interactive services would be better suited for individuals in earlier stages of cognitive impairment, and all involved need to ensure that technical partners have a clear comprehension of the technical abilities (and desires) of the participants. For example, several informal caregivers were frustrated by receiving text message alarms during all hours of the day, reporting that this made them feel they should be "on duty" 24 hours a day. To alleviate this, some alarms are directed to email or through the formal caregivers first, depending on the needs of the dyad. The informal caregivers report that the largest impact they notice is reassurance for the safety of the person with dementia (through checking activities in the home, location outside of the home, notifications for unusual events, and easy contact through the Touchscreen). The reminders, orientation to the day and for the structure of the day, tracking (GPS) device, home activities monitoring, and Touchscreen contact button are viewed most positively. They provide awareness about the activities of the person with dementia, increased feelings of safety and independence, peace of mind, and helped save time and costs associated with phone calls and visiting the person with dementia to check in on them. The reminders service was widely used and is a flexible service that the caregivers can adjust. For some of the dyads, the individuals with dementia were more likely to listen to the "third person" Carebox, and the reminders helped improve the relationship and reduce aggressiveness. However, the service was also identified as less useful with degradation in cognition.

The formal caregivers report that all participants seem to feel safer and less anxious, emphasizing that the caregivers being more aware of and reassured about the home situation through the monitoring reduces stress. They find the telecare system has improved and supported independence in the daily life for the person with dementia, and has benefitted the caregivers even more. The project provides the opportunity to gain knowledge from testing the dementia care intervention in realistic conditions and on the quality of the intervention experience. The qualitative information, and the responses to global questions, provide complementary angles to interpret the quantitative results.

Summary of gerontechnology intervention outcomes:

The intervention services were used for a mean of 193 days. The actual range is broad, due to cutbacks in the public sector in the 2009 European economic crisis; the Greece region has the lowest mean length of use at 137 days. The intervention group shows significant declines in IADL and QOL-AD, which are found to be significantly correlated. When dichotomized by length of use, there is a highly significant difference between the groups in SQLC, and it is the short use group that shows significant improvement (mean length 109 days). Furthermore, the short use group IADL shows a highly significant correlation with ADL, which is not present in the long use group. When the intervention group is divided by positive and negative effects in ZBI, the group with positive effects also used the intervention for a shorter mean length (167 days). In this same subgroup, there is a significant correlation between length of use and SQLC (non-significant) improvement. There is no significant evidence that using the gerontechnology intervention longer brings more positive outcomes.

One of the main conclusions that can be made about the results of the additional (non-standardized) questionnaires, is that there are some differences between how the participants report global outcomes from the intervention, and what the standardized assessments (defined domains) reveal. Both sets of results are based on participant reporting so both are considered to be honest evaluations; however, since the construct validity is unknown for the additional questions, comparisons with the standardized questionnaires is speculative. In the additional questions, none of the participants report decline and the majority report improvement in the 4 domains assessed. When looking at raw percentages, there is some agreement among the standardized and the non-standardized questionnaires. For physical and independent functioning, over 80% of participants show positive effects in ADL and around 61% show positive effects in IADL. To compare, around 61% of participants report an increase in independent living on the non-standardized questions. Just under half of the participants show positive effects in QOL-AD, and over 62% report increases through the additional questions. However, the negative effects in the standardized assessment outcomes are greater than the positive effects, and there is an overall (non-significant) decline in ADL, significant decline in IADL, and significant decline in QOL-AD. For the caregiver's quality of life, over 70% of participants reported increases, which agrees with nearly 65% showing improved SQLC scores. When the intervention participants are separated by living arrangement, the caregivers of individuals with dementia who live alone, have higher SQLC scores but smaller improvements. When dichotomized by length of use, the participants who use the technology longer, mostly live alone, also have significantly higher SQLC scores, but show decline that is highly significantly different from the shorter group's increase in SQLC. For caregiver burden, over 61% report decreases in care responsibilities, and almost 65% show positive ZBI outcomes. Furthermore, the 35,5% who show negative effects in ZBI corresponds to the same percentage of those who report maintained care responsibilities. The standardized assessment outcomes concerning the caregivers show (non-significant) improvement in SQLC and ZBI, indicating that the intervention has more direct positive effects for the caregivers than for the person with dementia. The two regions who used the intervention longer than the overall mean of 193 days both show 100% willingness to use services like the ones offered. 62,5% of the intervention participants report that they would be willing to pay for services like the ones offered, and this attitude aligns more to the results of the non-standardized assessments (where none report decline in conditions) than to the standardized assessments (where the caregivers show small improvements).

The project collected a wide range of information from testing and evaluating the gerontechnology intervention for dementia care. It was highly motivated, but complex, research that analyzes data from real-life testing from multiple angles. The qualitative information gives more insight into the development, use, and evaluation of the dementia telecare intervention. The reliability, stability, and accuracy of the telecare system are essential not only as technical requirements, but for the service functioning. Although all were achieved in the ISISEMD project, there were more technical problems encountered than were anticipated. This led to more home visits to resolve technical issues and reinforce training, and meant that the system was being optimized during testing. While it is unclear if the initial technical problems influenced the assessment outcomes, the recommendation is that the testing of the technologies should ensure a reliable system before starting real-life testing. This not only will help to resolve technical issues and perceptions on service credibility, but alleviates ethical concerns about testing unstable telecare services in the homes of people with dementia.

It is challenging for the adults with dementia to use technologies that are new to them, this is noticed particularly for the interactive services. Some services that are appropriate for individuals in the earlier stages of dementia will not be appropriate for those in the later stages. For example, caregivers noticed that the reminders service, although helpful, is less useful as cognition declines. It is important that the technical partners receive well-defined user requirements (as far as technical competency and service requests). Despite the challenges encountered, the system provides a secure living situation and effective risk management, which promote aging in place and benefit those involved in the dementia care. Services that are predominantly found useful are the Carebox services (reminders, orientation to the day, structure of the day, and contact button), sensors for home activity monitoring, and GPS locating services. The individuals with dementia conveyed increased feelings of safety and independence; however, the benefits seem to be greater in the caregivers. Previous research shows that the most important benefits that technology provides to caregivers are in saving time (77%), easing care logistics (76%), safety (75%), increasing feelings of effective caregiving (74%), and reducing stress (74%); caregivers will be most interested in technology interventions that will support them in delivering, monitoring, tracking and coordinating care [76]. Similar desired results are found from the ISISEMD project, adding strength to the external validity. The intervention allows caregivers to have an awareness about the person with dementia and their activities, which provides reassurance for safety, and saves time and costs on phone calls and visits. The intervention appears to bring the psychological benefits of reduced stress (anxiety, worry) and brings peace of mind. The fact that the caregivers give positive global and qualitative evaluations and express a desire to continue using it, indicates that they perceive the intervention to have had a noticeable and positive influence on their dementia care and lives. This information did not come across in the standardized assessments, and it is likely that there are other assessments that would more closely match the caregivers' perception on the usefulness of the system. A cautionary recommendation for such future research would be to keep the number of assessments to a minimum to avoid burdening the participants, and to consider the psychological effects of the questions in the assessments. The formal caregivers in the regions are a crucial part of the research project, in recruiting and training participants, and in administering assessments. Furthermore, they enhance the project cohesion with other partners, and provide valuable insight into the participants' context. Integrating them further into the research as partners will be beneficial.

5.7 Discussion of the analysis

The null hypothesis will be rejected if the results show maintained or increased physical and independent functioning, quality of life, and maintained or decreased caregiver burden when compared to the control group. The hypothesis is tested by looking for significant differences and between the groups, and the use of the technology is tested by looking at changes within the intervention group. The results of the hypothesis testing are given in Table 25.

Physical functioning of the individual with dementia

Both intervention and control participants exhibit statistically significant declines in instrumental physical functioning (IADL). This in itself was not an unexpected result, as dementia is a syndrome characterized by a progressive loss of abilities. Declines in IADL could be related to quality of life for both groups of participants, as the adults with dementia have less independence in self-care abilities and the caregivers have more tasks. When looking at the proportion of the intervention group who shows positive effects in both ADL and IADL, the majority of participants do show positive effects (80,7% and 61,3%, respectively), but this is quite similar to the control group's proportions (86,4% and 54,5%, respectively). When the outcomes in basic (ADL) and instrumental (IADL) activities of daily living are tested for a linear relationship, the intervention group shows a highly significant correlation and the control group shows a non-significant correlation. When the intervention group is further split into groups of short and long use, the group who used the technology 203 days or less show a highly significant linear correlation between the declines in ADL and IADL. Despite this, 100% of the intervention group participants gave positive results on the global question of support in independent living, with 61,3% reporting an increase in independent living. Although no comparative global view is available from the control participants, we can see that the intervention group did not find that the telecare impeded independent living. These results are not necessarily in contrast to the percentage of positive ADL and IADL outcomes, but show incongruity with the statistical significance of the defined decline.

The statistical results cannot reject the null hypothesis as the groups show similar decline. These results do not support the hypothesis that using technology would have a positive effect on quality of life.

Quality of life of the individual with dementia

Paired *t*-tests reveal that the intervention group has a significant decline in QOL-AD and the control group has a non-significant decline. 58% of the intervention participants show declines in their QOL-AD; in comparison, 54,5% of the control group shows QOL-AD decline. The intervention group's significant decline in QOL-AD is measured against the significant decline in IADL through a Pearson's correlation. The highly significant linear relationship shows that declining instrumental physical functioning and declining older adult quality of life have a high probability of influencing each other in the intervention group. There is disagreement in the positive global feeling of maintained or increased quality of life in the older adults, and the intervention group's significant decline in QOL-AD; 63% of the participants report global quality of life as being improved, this is slightly higher than the 42% who show positive effects through QOL-AD. Although it is unknown how they arrived at the overall conclusions, the majority of the intervention group perceived the services to have a positive effect on quality of life. Aside from the linear correlation with IADL decline, the available data does not allow for a concrete interpretation of why QOL-AD would decrease or how older adults arrive at conclusions about their QOL. It could be hypothesized that the QOL-AD is assessing specific domains that may be more likely to be associated with loss of ability or activity, but more research is needed.

The statistical results cannot reject the null hypothesis as the intervention group shows more decline than the control group. These results do not support the hypothesis that using technology would have a positive effect on quality of life.

Quality of life of the caregiver

The intervention and control groups both show increases in caregiver quality of life (SQLC). The independent *t*-test between the two groups show that there was low probability that the intervention group has different outcomes than the control. An analysis on the intervention length of use and quality of life shows that there is a highly significant difference between caregiver quality of life (SQLC) in the intervention groups based on length of use. The caregivers who used technologies longer have a mean decline in SQLC, while the caregivers using technologies less than 204 days have a mean increase in SQLC, and this difference in SQLC is significant difference between the short and long use intervention groups. One could expect that longer use of assistive technology would yield better quality of life outcomes, particularly if there was an adjustment period and technical issues when the intervention was first introduced. However, since the SQLC scores do not have a linear relationship with any of the other assessment scores, the probability of the improvement in caregiver quality of life being due to the shorter use of the intervention is low. The conclusion cannot be made that using technologies, or using technologies for a longer amount of time, results in more positive effects on quality of life. Nearly 65% of the intervention participants show positive effects in their SQLC outcomes, and 68,2% show positive effects in the control group. There is some agreement regarding the global feeling of maintained or improved caregiver quality of life and the non-significant improvement in SQLC. Regarding the global question on the caregiver's quality of life, 100% of the intervention participants who responded report positive effects and 70,9% of those report that it increased. While the intervention group reports that the telecare increased quality of life, there is no evidence of a significant relationship between using the intervention and better QOL outcomes for the caregivers.

The statistical results cannot reject the null hypothesis as the groups show similar improvement. These results do not support the hypothesis that using technology would have a positive effect on quality of life.

Caregiver burden and responsibilities

Comparing caregiver burden (ZBI) between the control and the intervention group caregivers shows a highly significant difference in outcomes between the two groups. A Pearson's correlation tests if the control group's significant decline in IADL was influential on the significant increase in ZBI. There was no evidence of a strong linear relationship and there was a low probability that the two of these influence each other; the decline in instrumental physical functioning did not increase caregiver burden in the control group. The result is that those who did not use technology experienced a highly significant increase in caregiver burden, and the caregivers who did use technology had a non-significant reduction in their caregiver burden. There is a significant difference in caregiver burden between the two groups and a statistical association (but a weak linear correlation) between IADL and ZBI in the control group. The Pearson's tests find no evidence that any changes in assessment scores to have strong linear relationships to ZBI scores in either group, including after dichotomization. The intervention group's non-standardized responses show maintained or decreased care responsibilities and the ZBI confirms that caregiver burden decreased, though non-significant at p=0,51. Again, 100% of the intervention caregivers report maintained or improved care responsibilities and almost 65% show positive effects in their individual ZBI scores, compared to only 31,8% of individuals showing positive effects in the control group.

The statistical results can reject the null hypothesis as the intervention group shows more improvement than the control group. These results support the hypothesis that using technology would have a positive effect on quality of life.

Overall difference in outcomes from using gerontechnology intervention

The changes in the groups are compared in an independent *t*-test. The mean outcomes from the assessments (MMSE, MoCA, ADL, IADL, QOL-AD, SQLC, and ZBI) are tested to reveal if the differences in the groups is less than 5% due to chance. The results show that the difference between the outcomes is not significant at p=0,44.

The statistical results cannot reject the null hypothesis as the outcomes from being in one group or the other are not significantly different. These results do not support the hypothesis that using technology has a positive effect on quality of life.

Table 25 Results of research questions and hypothesis testing, incl. DK n=53

Research question	Variable and outcome	Assessment for validation	Method of aggregation	Hypothesized outcome	Observed outcome
1. Will using gerontechnology have positive effects on physical and independent functioning?	Physical and independent functioning Secondary outcome	ADL and IADL	Compared means between groups	H_1: Intervention group will show improvement or less decline than the control group H_0: Intervention group shows no significant difference from the control group	H_0: The two groups do not show significant differences in ADL (p=0,40) or IADL (p=0,83) outcomes
	Physical and independent functioning Secondary outcome	Non-standardized questionnaire on feeling of change in independent living	Post hoc mean from intervention group	H_1: Intervention group will report an increase in independent living H_0: Intervention group will report no change or decrease in independent living	H_1: The intervention group reports an increase in independent living for 61,3% of participants and maintained independent living in the remaining 37,1%
2. Will using gerontechnology have positive effects on QOL in the person with dementia?	Quality of life Primary outcome	QOL-AD	Compared means between groups	H_1: Intervention group will show improvement or less decline in QOL-AD than the control group H_0: Intervention group shows no significant difference from the control group's QOL-AD	H_0: The two groups do not show significant differences in QOL-AD outcomes (p=0,64)
	Quality of life Secondary outcome	Non-standardized questionnaire on feeling of change in QOL	Post hoc mean from intervention group	H_1: The intervention group will show an increase in QOL for 50% of participants with dementia H_0: Intervention group will report no change or decrease in QOL	H_1: The intervention group shows an increased QOL for 62,9% of participants with dementia and maintained QOL for the remaining 37,1%
3. Will using gerontechnology have positive effects on QOL in the caregivers?	Quality of life Primary outcome	SQLC	Compared means between groups	H_1: Intervention group will show improvement or less decline in SQLC than the control group H_0: Intervention group shows no significant difference from the control group's SQLC	H_0: The two groups do not show significant differences in SQLC outcomes (p=0,93)
	Quality of life Secondary outcome	Non-standardized questionnaire on feeling of change in QOL	Post hoc mean from intervention group	H_1: The intervention group will show an increase in QOL for 70% of caregivers H_0: Intervention group will report no change or decrease in QOL	H_1: The intervention group shows an increase in QOL for 70,9% of caregivers and maintained QOL for the remaining 19,4%
4. Will using gerontechnology have positive effects on caregiver burden?	Caregiver burden Secondary outcome	ZBI	Compared means between groups	H_1: Intervention group will show improvement or less decline in ZBI than the control group H_0: Intervention group shows no significant difference from the control group's ZBI	H_1: The intervention group has significantly better outcomes in ZBI (p=0,03*)

Research question	Variable and outcome	Assessment for validation	Method of aggregation	Hypothesized outcome	Observed outcome
	Caregiver burden Secondary outcome	Non-standardized questionnaire on feeling of change in care responsibilities	Post hoc mean from intervention group	H_1: The intervention group will show reduced care responsibilities by 60% H_0: Intervention group has no effect on or increases care responsibilities	H_1: The intervention group shows care responsibilities were reduced in 61,3% of caregivers and care responsibilities were maintained in the remaining 35,5%
5. Will using gerontechnology have positive effects on safety in the home?	User safety Secondary outcome	Non-standardized questionnaire on feeling of safety in the home environment	Post hoc mean from intervention group	H_1: Participants will report feeling safer with the telecare system H_2: The intervention group will show an increase in feeling of safety in 30% of participants H_0: Intervention group has no effect on or decreases feeling of safety	H_2: The intervention group shows an increase in feeling of safety in 80,6% of participants and maintained feeling of safety in the remaining 19,4%
6. Will people be satisfied with the intervention system?	User satisfaction Secondary outcome	Non-standardized questionnaire on feeling of satisfaction regarding the system	Post hoc mean from intervention group	H_1: Participants will report being satisfied with the telecare system H_2: 75% of participants will report being satisfied with the telecare system H_0: Intervention group has no effect on or increases care responsibilities	H_2: 88,7% of participants report being satisfied with the telecare system
7. Will end users be willing to pay for gerontechnology services?	User acceptance Secondary outcome	Non-standardized questionnaire on willingness to pay for services.	Post hoc mean from intervention group	H_1: Participants will report willingness to pay for telecare services. H_0: Participants will not be willing to pay for telecare in place of usual care.	H_1: 58,1% of participants with dementia and 48,4% of caregivers report willingness to pay for telecare services.
8. Would people want to use services like these?	User satisfaction Secondary outcome	Non-standardized questionnaire on willingness to use services.	Post hoc mean from intervention group	H_1: Participants will report a desire to continue using telecare services. H_2: 75% of intervention caregivers will report a desire to continue using services H_0: Participants will not want to continue using telecare services.	H_2: 90,3% of intervention participants report at least considering continuing to use the services
Overall difference	Primary outcome	ADL, IADL, QOL-AD, SQLC, and ZBI	Compared mean changes in the 5 assessments	H_1: Intervention group Participants will have significantly different (better) outcomes.	H_0: The two types of care do not show significant differences in outcomes (p=0,48)

The background chapter described the increasing demand for dementia care. It is a specific area of caregiving that requires adapting to the individual's transient and declining state; it is truly person-centered care. There is also an increasing use of supportive technology in dementia care. Assistive Technology is perceived as beneficial by focus groups, based on their intuitive knowledge of caregiving. People will use and seek Assistive Technology that has obvious benefits for their needs, and to assist with dementia care is to take action to improve the health and safety of a person with dementia. The very nature of the intervention is intended to improve quality of life, i.e. assisting with care. If both the need (e.g. support in monitoring and ensuring the safety of the person with dementia) and motivation (e.g. personal weighing of pros and cons) for using ATs are present, and the technology is perceived as beneficial, it remains a quagmire that the obvious perceived benefits are not represented in data. One possible reason is insufficient consistency in the research, which makes comparing results complicated and uncertain. With many methodological strategies, the field can become as heterogeneous as the study population themselves. Using the theories can provide structure to understanding the scope of the results; the theories should explain the observations and make projections for the results of subsequent observations.

Phenomenology motivates user-driven design and person-centered care, and can shed light on the variation in outcomes at an individual level. Exponential growth is a motivation for further gerontechnology research and application. Gerontology theories can be applied to interpret the outcomes. According to the biomedical model, the participants with dementia in ISISEMD are precluded from aging successfully as there is the presence of physical and cognitive impairment. However, research shows that successful aging can be predicted by mental health and social relationships [109]. Assessing one aspect of mental health through the MMSE and MoCA scores shows that both groups, on average, declined. The group mean changes show evidence of cognitive impairment, while the majority of the individuals show maintained or improved cognition. The quantitative results can be used to both demonstrate and negate the successful aging of the participants with dementia. In the intervention group, 15 out of 28 (53,6%) showed maintained or improved MMSE scores, and 17 out of 28 (60,7%) maintained or improved MoCA scores. In the control group, only 8 out of 22 (36,4%) maintained or improved MMSE scores, and 11 out of 20 (55%) maintained or improved MoCA scores.

There was no indication of learned dependency during the ISISEMD project, although it should be considered with longer use of telecare. Regarding learned helplessness, if anything, examples were found of increased confidence, where participants who had been afraid to be alone before, now felt comfortable doing so with the technology. The feedback from the participants was used to tailor the services, providing a feedback loop of co-creation, which helped avoid learned dependency through supporting intact abilities. For example, when appropriate, the participants with dementia were first alerted to turn off the stove so that they had the opportunity to amend the situation before caregivers would be contacted. Activity theory and social constructivist theory can be used to interpret the positive effects from the cycles of co-creation. Participants exhibited the activity of using the services and provided feedback for further adaptation of the services to their needs. Adapting the services required considering the individual, the caregiving dyad, their history, home environment, role of the technology as a mediator, and the complexity of the activities and their appropriateness for the participant. After the adjustments, users adapt to the services, and the services can be further adapted to the users, in a cycle of co-creation of both activity and technology. Allowing the participants to co-create or adapt the services to their needs promotes involvement in activities and activity theory would hold that this cycle promotes positive effects on quality of life. Social constructivist theory would speculate that the technology and society also co-construct each other in the real-life context through the adaptation of social practices (not only in social interactions, but through social and health service provision) and the technology (through tailoring the services). Another aspect of tailoring the services was the importance of the phenomenology of the end users' experiences with the telecare. For example, one participant with dementia could no longer use a telephone, but he could use the contact button on the GPS device to contact caregivers. The device had a realistic use of providing contact to help, and also had an existential effect in that now the participant could independently and safely leave the home, which relates to his perception of self. When taken at an individual, phenomenological perspective, this one service had real benefits for the dyad, and the impact of this on their lives was not observable in the quantitative data. When only the participant's scores are the overall outcomes, the relative validity is overlooked.

Activity theory would hypothesize that decreased activity would cause individuals with dementia to experience decreasing life quality. As discussed in the section on quality of life, activity theory plays a large role in identifying domains to be evaluated in quality of life assessment tools for individuals with dementia (i.e. ADLs and IADLs). In the example of no longer being able to cook for oneself, it would be limiting in scope to deduce that decreased cooking activities results in decreased QOL. It is conversely unfounded to deduce that increased cooking activities with the help of technology results in increased QOL. In support of activity theory, some participants used the technology to be active (i.e. taking walks, shopping, socialization), but this is not reflected in a global assessment score. Participants in both groups showed decline in independent physical functioning and in quality of life; however, the system fostered independence through reminders, and alerts could first be presented to the older adult on the Carebox screen, allowing them to amend the situation before a caregiver would be contacted. The intervention group's correlation between the person with dementia's report of QOL-AD and both ADL and IADL is interesting since the caregiver's score and weighted score do not have strong correlations with ADL and IADL outcomes. The person with dementia's QOL-AD assessment is highly correlated with assessments of their physical functioning, which could support previous research on individuals with dementia and their ability to accurately evaluate their own quality of life [45] [177] [181]. However, this could also be related to the technology use, since the control group does not have strong correlations with QOL-AD and ADL/IADL. Perhaps using the services (and technologies) makes them aware of their abilities (which the person may compensate for when around others), that they accurately reflect in their QOL-AD assessment.

The field of gerontechnology is relatively young and there is not a vast body of evidence to understand older adults' interaction with technology nor about the outcomes from telecare use. As in previous research [307], the ISISEMD project found that medical professionals, caregivers, and individuals with dementia did not have clear understanding about how technologies can assist in dementia care, and needed to be educated about the options available and expected benefits. Problems in dementia care are usually addressed in both numbers and words (e.g. stage of dementia and description of the symptoms), and describing intervention outcomes in a similar manner may be more effective in reaching medical professionals and caregivers (i.e. 64,5% of caregivers using the technology have positive outcomes in caregiver burden and the system successfully alerts for unintended exits in the middle of the night). The data analysis alone does not illustrate the full experience of continued growth and development in the older adults. Those who interacted with the technology (i.e. GPS device or touchscreen computer) were demonstrating a willingness and motivation to learn to use the technology, and this is not represented in the quantitative analysis. In light of social constructivist theory, several of the participants would tell of how they would use the technology to suit their needs, often in inventive ways that the project partners had not considered. The innovative interaction with the technology also supported the phenomenological perspective of the participants, demonstrating how they would find value in the devices and services. One woman would use the contact button to call her caregiver, although the project partners had originally designed this feature to be for emergencies, they redesigned the contact button GUI to reflect its use for general contact rather than emergency help. One gentleman told how he would keep the GPS device in his coat pocket at all times, even while it was charging, so he would not forget it when he left the house. Others put a picture of the GPS device on the front door, to remind themselves to take it with when they were leaving the house. The results from the non-standardized questions pose an interesting contrast to the quantitative results. The responses to the questionnaires show that the intervention group older adults and caregivers report feeling positive effects on quality of life for both themselves and the other. Likewise, the participants report positive effects on independent living and caregiving tasks. It is intriguing that the subjective results would be in such contrast with the quantitative results, and certainly raises the question of whether the standardized assessments are more or less accurate in capturing global effects on quality of life. It could be that defining the domains of quality of life to be assessed is too narrow or that the participants did not consider what they would define as quality of life and answered based on a general feeling. Perhaps the knowledge gap is not only in the lack of evidence, but in *why* it is difficult to attain valid data for the evidence base.

Data analysis summary:

The focus of this research is in collecting evidence on technology use in dementia care and outcomes in quality of life. Responses to global (non-standardized) questions on independence, quality of life, and caregiving tasks were also reported. The results showed that all of the participants felt positive effects on their own quality of life as well as for the other individual. Some of these responses are in contrast to the standardized assessment outcomes.

There were not significant differences between the control and intervention groups' outcomes in cognition (MMSE and MoCA). Both groups exhibit significant declines in instrumental physical functioning (IADL) but only the control group exhibits a highly significant increase in caregiving-related stress. This could indicate that the use of technology defers caregiver burden despite significant functional decline. Both groups of older adults have decline in their instrumental physical functioning (IADL). Likewise, both groups show decline in their quality of life (QOL-AD), but only the intervention group shows significant decline. The intervention group exhibits a highly significant, positive linear relationship between QOL-AD and IADL outcomes. When the intervention group is dichotomized by positive and negative outcomes in QOL-AD, the participants' decline in QOL-AD shows a highly significant, positive linear relationship with their IADL decline. In the intervention group, significant declines in independent functioning and quality of life of the person with dementia are highly correlated. The intervention group has a highly significant correlation between caregiver quality of life and length of use; however, it the caregivers who used the technology less than 204 days who have greater increases in their SQLC. There are no other significant differences between the short and long use groups of intervention caregivers and the shorter group's SQLC is not strongly correlated with any other variable. The conclusion is that there is a low probability that the increase in SQLC is due to shorter use of technology. Though the caregivers in both groups have increases in their quality of life (SQLC), only the control group has a highly significant increase in their caregiving-related stress (ZBI) as well. This shows that although both groups have increases in their quality of life (SQLC), the intervention group has a reduction in their caregiver burden (ZBI) and the control group had an increase in theirs. The technology intervention in dementia care has a positive effect for the caregivers by reducing their caregiver burden (ZBI). Although this is not reduced by a statistically significant amount within the intervention group, it is a highly significantly different from the caregivers who did not use technology. Further tests show that no other variable is correlated with the change in ZBI score in the intervention group, so it is deduced that it is due to the influence of technology. This difference between the control and intervention group ZBI is the strongest objective evidence to support the hypothesis that using technology can improve quality of life in dementia care.

This study presents the outcomes from using a gerontechnology intervention in dementia care, and compares them to a control group. Results are derived from mixed methods (standardized assessments, non-standardized questionnaires, observations, and qualitative information), and the theoretical implications are also discussed. The following research questions were proposed, investigated, and discussed:

1. Will gerontechnology use have positive effects on physical and independent functioning? In both groups, ADL and IADL has average decline, and there is not a significant difference between the control and intervention groups. The exploratory results from the global questions show that gerontechnology did have positive effects on independent living. 61,3% of participants in the intervention group report increased independent living, and the qualitative information further finds independence is perceived as increased. The comparative results show that gerontechnology use did not have significantly different effects on functioning than usual care.
2. Will gerontechnology use have positive effects on the quality of life of the person with dementia? The intervention group shows a significant decline in QOL-AD, but the outcomes are not significantly different from the control group. In contrast, the exploratory results show that gerontechnology did have a positive effect on quality of life for the person with dementia as 62,9% of the intervention participants self-report improved QOL in the global question. The comparative results show that gerontechnology did not have significantly different effects on quality of life for the person with dementia than usual care did.
3. Will gerontechnology use have positive effects on the quality of life of the caregiver of the person with dementia? While SQLC increased in both groups, there is not a significant difference between the two groups. The exploratory results do show that gerontechnology has positive effects on the quality of life in caregivers as 70,9% of participants report increased quality of life for the caregiver in the global question. The comparative results show gerontechnology use did not have significantly different effects on caregiver quality of life than usual care.

4. Will gerontechnology use have positive effects on caregiver burden? There is a significant difference in ZBI between the control and intervention groups. The control group shows a significant increase in burden while the intervention groups shows a non-significant improvement. The exploratory results from the intervention group show that gerontechnology has a positive effect on caregiving responsibilities as 61,3% report decreased care responsibilities on the global question. The exploratory results corroborate with the 64,5% of the intervention caregivers who have positive effects in their ZBI outcomes. The comparative results show that gerontechnology use did have positive effects on caregiver burden that were different from in usual care.
5. Will people feel safer when using the telecare system? 80,6% of the adults with dementia and their caregivers report increased feelings of safety. The exploratory results show that gerontechnology use did have a positive effect on feelings of safety
6. Will people be satisfied with the telecare system? 88,7% of the participants reported being satisfied. The exploratory results show that users were satisfied with the telecare system.
7. Will people want to use dementia care intervention services like these? 90,3% of all the intervention group participants would consider or definitely want to use an intervention like this. The exploratory results show that users will want to use services like these.
8. Will end users be willing to pay for gerontechnology intervention services like this? 53,2% of the intervention group participants would be willing to pay for the services. The exploratory results show that users are willing to pay for services like these.

Post hoc ergo propter hoc cautions that before-and-after is not synonymous with cause-and-effect, reminding us that correlation does not equal causation. The data analysis shows more positive effects for the caregivers than for the person with dementia, and caregiver burden is the only significant outcome between the two groups. The results show that the technology intervention has more positive effects for the caregivers than for the older adults with dementia. The global and qualitative results show positive perceptions of the intervention and that it improved key areas considered indicative of quality of life. Furthermore, the majority of intervention participants are willing to pay to use such services, and it is unlikely that they would rate global outcomes so positively and be willing to pay for services that provide only marginal benefits for caregiver burden, as the statistical analysis suggests. To summarize, there is evidence of an association between gerontechnology in dementia care and positive outcomes in caregiver burden; however, there may be confounding variables (e.g. education level, type of dementia, length of caregiving). The global and qualitative results indicate that the intervention has a positive effect on independent living, safety, caregiver responsibilities and stress, and quality of life. The research goal is to add to the evidence-base on gerontechnology outcomes in dementia care. While the technologies are effective at supplementing best practices in dementia care, the two types of care did not produce significantly different outcomes. Both methods of caregiving have similar effective on quality of life and the null hypothesis cannot be rejected.

Papers supporting Chapter 5:

More information on the outcomes from the project can be found in Papers D, E, G, H, and in ISISEMD project reports. Paper D presents results up to the mid-term evaluation of the ISISMD project and includes qualitative information from the participants. Paper E presents outcomes as well as lessons learned from the research project. Paper G specifically addresses the outcomes in caregiver burden, including qualitative information, and Paper H focuses on outcomes for caregiver quality of life.

Chapter 6. Discussion of the research

The purpose of this research is to investigate the outcomes of using technologies in home-based dementia care, as much of the current information is anecdotal. The data analysis showed that using technologies in dementia care has a positive effect on the quality of life of the caregivers by preventing significant increases in burden. However, taking the results at face value can be misleading, so a discussion of the research and results is presented, considering the methods and tools used, strengths and weaknesses of the study, and future directions in the field of gerontechnology. The hope is that these outcomes are taken into consideration so that evidence-based decisions can be made about technologies in dementia care.

Papers included in Chapter 6:

The results of the mid-term evaluation are given in Paper D. Paper D also describes changes to the methodology.

> Paper D: Anelia Mitseva, Carrie Beth Peterson, Christina Karamberi, Lamprini Ch. Oikonomou, Athanasois Mpallis, Charalampos Giannakakos, and George E Dafoulas. "Gerontechnology: Providing a helping hand when caring for cognitively impaired older adults – intermediate results on the satisfaction and acceptance of informal caregivers from a controlled study." *Current Gerontology and Geriatrics Research*, Hindawi Publishing, Article ID 401705, 2012. DOI: 10.1155/2012/401705. 19 pages.

Paper F discusses future perspectives of technology in dementia care.

> Paper F: Carrie Beth Peterson, Neeli R Prasad, and Ramjee Prasad. "The future of assistive technologies for dementia." *Gerontechnology 11(2)*, p. 195. 2012. DOI: http://dx.doi.org/10.4017/gt.2012.11.02.427.742. 7 pages. Awarded "Best Paper" at the International Society for Gerontechnology conference, 2012.

A literature search in order to compare results in ZBI can be found in Paper G, which specifically discusses the outcomes in caregiver burden. A deeper discussion on the significance of the outcomes for caregivers and the relevance for individuals, health and care providers, and policy makers can be found in Paper G.

> Paper G: Carrie Beth Peterson, Lars Bo Larsen, Poul Svante Eriksen, and Ole K Hejlesen. "Zarit burden interview shows decrease in caregiver burden with technology intervention in European dementia study." Submitted for publication to the *British Medical Journal*, 2014.

A detailed discussion specifically on the differences in SQLC across the regions can be found in Paper H

> Paper H: Carrie Beth Peterson. "Results from a clinical trial on gerontechnology in dementia care and caregiver quality of life outcomes." Technical report, 8 pages, 2013.

6.1 Discussion of the methods and tools

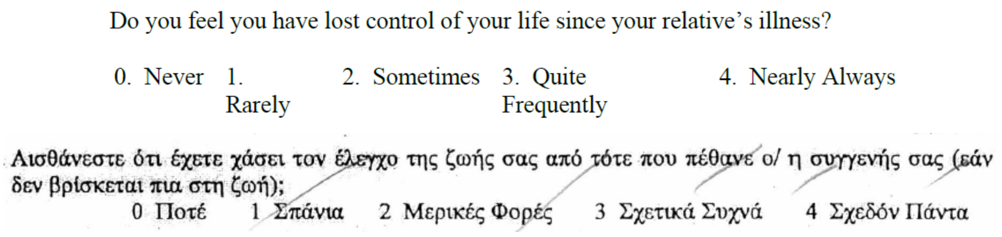
Standardized evaluation tools were used to assess the quality of life of the end users in both groups. From an administration point of view, the evaluation of the outcomes was a complex task. First of all, there were concerns that the number of assessments was too many to administer in one sitting. In all, 7 standardized assessments were given at the baseline and final evaluations (i.e. MMSE, MoCA, ADL, IADL, QOL-AD, SQLC, and ZBI), with some regions also administering assessments during a mid-term evaluation. The results of the mid-term evaluation are given in Paper D.The intervention group answered additional questions through non-standardized assessments of their acceptance and satisfaction with the system and services. The sheer number of questionnaires can cause stress and fatigue. Furthermore, the fact that they were administered face-to-face and in a serial order, poses the possibility of carryover and order effects, and interviewer bias.

Although widely used in both healthcare and research, there have been criticisms of the MMSE, most notable are the differences in administration methods and score interpretation (not always done by neuropsychologists) [308] [309]. Authorized translations in Danish, Finnish, Greek, and UK English are available from Psychological Assessment Resources, Inc. (PAR) at http://www.minimental.com. Across cultures, the educational level, language ability, age, co-psychopathology (i.e. symptoms of both dementia and depression), and socioeconomic status of individuals can influence the ability to give responses to the assessment, and thus influence the validity of the interpretation [310]. Furthermore, individuals with different geographical and cultural backgrounds perceive and manage daily problems in different ways. The difficulty of the questions, the range of competencies that the questions can differentiate, and the ability to guess (correct) answers can all be affected in cultural translations. It is unknown if participants outside the Denmark region were minorities who did not have the cultural background of the region they were living. Although information can be found on the use of the MMSE in Denmark [311] [312], Finland [313], Greece [314], and Ireland [315], the cultural validity in the countries is yet unknown.

While transferring the raw assessments from the regions to the original English versions, several major impediments came to light. Although they were standardized and approved assessment tools, there were important differences that had not been discovered before (either by the partners or in the literature review). Variations in the assessments were noted specifically for the IADL, SQLC, and ZBI instruments. It is unknown why there are differences among the assessments, and further research in this area would be beneficial. A detailed discussion specifically on the differences in SQLC can be found in Paper H. The differences in ZBI have been discussed with Dr. Steven Zarit and are being looked into by the Mapi Research Trust.

1. In the Greek version of IADL, there is the additional option of "does not participate in (activity)," that is not in the original English version of the other translated versions used in the study.
2. The Danish and Finnish versions of SQLC have different points than the original English version for question #10 "Does the regular everyday care and attention to the chronically disabled person make you depressed?"
3. The Finnish version of SQLC has different points than the original English version for question #3 "Did you change your work because of your relative's disease?"
4. The Finnish version of the ZBI short form only has 11 questions, whereas the original English and other translated versions have 12 questions, including "Do you feel you could do a better job in caring for your relative?"
5. Greek partners in the project chose not to ask ZBI question #9 to the participants, shown in Figure 32. They found this question to be specifically stressing to the caregivers and the project partners worried about the ethical implications of inducing distress. Upon further investigation, it was found that the Greek version mentions the relative's illness in a way that refers to death. It is unclear as to whether the implication of death was a cultural translation or if it was a translation error. This question was not removed from the other region's assessments.

Figure 32 Zarit Burden Interview question #9 in English and Greek



Do you feel you have lost control of your life since your relative's illness?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

Αισθάνεστε ότι έχετε χάσει τον έλεγχο της ζωής σας από τότε που πέθανε ο/ η συγγενής σας (εάν δεν βρίσκεται πια στη ζωή);

0 Ποτέ 1 Σπάνια 2 Μερικές Φορές 3 Σχετικά Συχνά 4 Σχεδόν Πάντα

Even when studies use the same tools, the results are still difficult to generalise. For example, one study reports outcomes of the 12-item ZBI in 413 caregivers over 6 months, but did not use technology intervention [295]. The mean ZBI was 20,59 (SD 15,64) at baseline, and 20,97 (SD 17,35) at follow-up, with an average increase of 0,35 (SD 12,21). We could expect similar results in our control group; however, the ISISEMD control group shows lower burden at both the baseline and follow-up evaluations (and smaller SD), but a greater increase in ZBI. The increase in ZBI could have been influenced by a number of factors (i.e. time between testing, age, caregiver relationship, gender, cognitive functioning, intervention, etc.), all of which differed between the two studies. This provides an example to illustrate the difficulties in comparing results from different studies, even when they use the same quantitative measures. Since the ZBI is the most discussed tool to evaluate caregiver burden, a literature search was conducted in order to compare this study's ZBI results with similar studies. The search was limited to reports which investigated technology services for dementia care, reported outcomes in caregiver burden, and were available in full text. Articles were excluded if they did not pertain to the 12-item ZBI, dementia caregiving, or technology intervention, and if they did not report results. Three relevant articles were identified but none provided comparable evidence to analyze. Searching the Cochrane Library for 12-item Zarit Burden Interview and dementia results in one study protocol that does not give results [205]. A PubMed search for 12-item Zarit Burden Interview, dementia, and technology intervention returns zero papers [316]. A Scirus search for the same keywords results in 282 hits [317], only 3 of which are relevant. Further discussion on this can be found in Paper G.

1. A 12 month trial on a night time monitoring system (bed and door sensors and alarms) with 53 participants in the USA assesses caregiver burden with the 12-item ZBI [318]. They report a mean baseline score of 2,79 (five times lower than the ISISEMD total mean of 14,44), and that the control group has significantly higher ZBI than the intervention group at baseline. However, change in caregiver burden is not one of their main hypotheses, so detailed information on burden outcomes is not given. They conclude that the monitoring system proves to be a reliable support for caregivers to manage night activity and find that the intervention group is 85% less likely to experience incidents than the control group.
2. A systematic review on intervention programmes for family caregivers finds, when excluding telephone-based support, no study is identified as a technology-based intervention [319].
3. A literature search on systematic reviews of interventions for caregivers identified 112 full text articles [320]; 15 of the reviews met the quality criteria, and only three of those pertained to technology-based interventions in dementia care. The authors find evidence on the effectiveness of technology-based interventions lacking in controlled studies, but uncontrolled studies indicate that GPS systems can be beneficial.

Not all the raw data was available to compare the assessment items for all individual with dementia and caregiver dyads, and a list-wise deletion was carried out in order to run statistical analysis on the dyads with complete data sets. This meant that some participants were eliminated from the analysis due to missing one or more scores for the assessments to be evaluated for the PhD study (i.e. ADL, IADL, QOL-AD, SQLC, and ZBI). It is noted that the 22-item ZBI was administered in Greece and the 12-item outcomes were taken from this, whereas the other regions used the 12-item form. This did not pose any statistical challenge as the 22-item form contained all 12 questions, but is a noted shortcoming of the project methodology due to the potential bias of administration error. Additionally, some of the adults with dementia had more than one informal caregiver provide data during the study (n=3), and the secondary caregiver data was not included in this analysis. The assessment tools evaluate a set number of indicators and the intervention services would most likely influence some domains and not others (i.e. ability to do chores around the house is more likely to be influenced than money). In this light, smaller global improvements were expected from the standardized assessments, but this weakens the significance of the overall quantitative results of the study. By looking at domains that the assessments measure, the individual real-life application of the intervention proves another angle of the usefulness than what the assessment outcomes can show. By assessing the scores in this way, a (cautious) comparison can be made for the changes that would typically occur in usual care and changes which may be influenced by the technology. By the conclusion of the 15 month the testing period, the control group shows more positive effects in QOL-AD scores (41,9% of intervention participants and 45,5% of controls) and SQLC scores (64,5% of intervention, 68,2% of controls). In the intervention group, physical functioning (ADL) outcomes were more positive than in the control group (80,7% of intervention, 86,4% of controls), as well as higher-level functioning (IADL: 61,3% of intervention, 54,5% of controls), and caregiver burden (ZBI: 64,5% of intervention, 31,8% of controls). While sufficient enough raw data (i.e. digital copies of the questionnaires) is not available to make the same comparison for the control group, the intervention group's detailed results exhibit real-life improvements in the quality of the lives of the participants. The specific domains and construct improvements include [272]:

- IADL
    - 50% of the intervention participants show positive effects in their ability to make phone calls
    - 40% show improvement in medication management
    - 60% maintained their ability to use transportation
    - 50% had positive effects in their ability to shop
- QOL-AD
    - 40% of of the intervention participants with dementia report maintained living situation
    - 50% report mixed maintained/declined living situation
    - 60% the intervention participants with dementia show maintained or improved relationships
    - 40% show maintained social life
- SQLC
    - 60% of the intervention caregivers had maintenance or improvement in their social life
    - 80-100% of the caregivers report maintained or improved employment status
    - caregiving tasks were maintained or improved in 60% of the caregivers
- ZBI
    - 64,5% of the intervention caregivers had maintained or improved caregiver burden, twice as much as in the control group

Yet, despite these positive effects that individuals actually experienced, the statistical analysis shows that the intervention did not have an overall significant effect. One explanation could be that the ability to answer the questionnaires does not imply that the questions have been understood; in longitudinal studies including self-reports by people with dementia, the questions (and constructs) can be perceived differently at separate assessment points [321]. When developing the assessment methodology, the choice of instruments were found to be robust and used in previous research on dementia care outcomes. It was hypothesized that the range of assessments would provide a multifaceted portrayal of the intervention's effects on overall quality of life in the dyad. However, the concept of quality of life has no gold standard to compare against leaving construct validity inexact, especially when comparing among individuals. It could be that global questions are easier to comprehend and report than defined constructs that require at least an understanding of the definition (i.e. social life); but, when attempting to intervene on domains that are suffering, defined constructs are necessary. The qualitative feedback does not support the quantitative results, which leaves doubts about the study's methods and the instruments' ability to detect meaningful outcomes. Researching changes in individual QOL in order to generalize wider population relevance presents a challenge of whether quality of life is considered a reliable and valid measure of the actual construct. The standardized questionnaires, although valid to assess their domains, could be missing some latent variables when attempting to evaluate the quality of life outcomes from a clinical intervention. This would help explain the disagreement between the statistical analysis and the qualitative analysis. It could be that there are closer outcomes than quality of life to detect the effects of the intervention, for example, hours spent giving care, environmental adaptation, or pleasant activities may have been better suited.

Another explanation could be in the nature of the research. This study focuses on non-pharmacological interventions which are relatively new to dementia care; it is a developing area between Assistive Technology, health outcomes, and gerontology. These areas of research often have different characteristics, methods, and goals from clinical research (i.e. the gold standard) [322]. Determining the clinical significance of non-pharmacological and palliative interventions is difficult, and this is further complicated by the subjective nature of the user assessment and the mixed methods design. Mixed methods has the benefit of providing various angles of the outcomes but increases the complexity of the study and interpretation of the results [270]. Correlation is present when two variables are found to modify each other; however, when discussing correlations in life quality, there are easily numerous influential variables and correlations become more elusive. With so many variables, it can be difficult to prove that the correlations hold absolute, generalized meaning. This is additionally complex as one technological device or service could serve multiple meanings to one person, and this will often vary between persons. By the time the implications are understood, the technology is already outdated and replaced with something exponentially advanced. The person with dementia and their caregiver dyad are known to have a heterogeneous nature; this patient population is best cared for on an individualized basis, and clinical significance can be obscured by the wide variations. The clinical gold standard of experimental modeling and quantitative results can fail to identify some useful benefits of the intervention that are present but not inquired about. The clinical implication of this research is discussed in Paper G on ZBI outcomes.

Carrie Beth Peterson, Lars Bo Larsen, Poul, Svante Eriksen, and Ole K Hejlesen. "Zarit Burden Interview shows decrease in caregiver burden with technology intervention in European dementia study." Submitted for publication to BMJ, 20 pages. 2014.

> If the majority of these studies have methodological issues, perhaps it is time to adjust the way that non-pharmacological and palliative dementia care interventions are validated. Holding dementia care outcomes to the same standards as traditional (e.g. biological) clinical research is relatively outside of the dementia care paradigm, as the syndrome cannot effectively be halted or prevented. How many points does caregiver burden need to be reduced in order to achieve clinically significant results? If using technologies to support caregivers can help to provide quality care in the home and delay or defer institutionalisation, it has implications for clinical significance. One only has to consider the host of problems that caregivers for someone with dementia face when they take on the role. As such, not taking action to support caregivers has pronounced public health consequences as the global incidence of dementia rises. Even though the reduction in intervention group ZBI was not statistically significant, it could be clinically significant for the caregivers to protect against significant increases in caregiver burden and the related health and well-being implications. As of yet, there is little definitive knowledge on the relationship between the clinical features of dementia and dementia caregiving, and assistive technology's suitability to intervene on specific symptoms. Clearer conceptual links are needed to support demonstrated effectiveness and to be sure that indicators of success are useful and meaningful to the persons the interventions are aimed towards helping. [269] While the qualitative information provides more insight to the intervention group's outcomes, no qualitative insight is available for the control group as to why their burden shows a highly significant increase.

6.2 Strengths of the study

One of the strongest points of the study was that it tested the telecare services across different European countries for over a year to obtain results on the real-life conditions of the end users. Furthermore, the services were tailored to accommodate the needs of the different organizational structures of care providers as well as the individualized user requirements of the older adults. Another noted strength of the study was the advantages of working in multidisciplinary teams that share expertise across technical, governmental, social care, medical, and academic levels. Although communicating the same ideas across the levels of expertise was challenging, the project partners reported that the cooperation was fruitful and overall helpful. The technical partners gained a better understanding of how services are perceived and used by end users in real life. The regional social and health care partners reported that their understanding of how technology could enhance their services to better serve their patient populations was improved, leading to more awareness about telecare services for older adults and about the technologies themselves. Additionally, they gained a clearer perspective on organization in order to offer eHealth services in their regions or to enhance eHealth networks that were already in place.

Despite the methodological difficulties, not only were the intervention outcomes assessed, but the telecare system was evaluated for reliability and robustness. The feedback from participants permitted tailoring of the services to the needs of the individuals; for example, some participants felt it was a “waste” to keep the screen on all the time, which was accommodated through motion-sensing activation of the screen. By including the participants’ opinions and experiences throughout the process, the interventions are targeted and allow the users to co-create their interventions. Despite problems recruiting participants, the sample population represents four cultures in Europe and scalable technologies were tested for 15 months, which is one of the longer periods reported for telecare interventions. The initial evaluation phase was planned for 12 months but was later extended to 15 months to accommodate the difficulties in recruiting participants and optimizing the system [275]. Furthermore, the intervention was tailored, multi-component, and long-term, all of which are recommended for implementing effective dementia care interventions [38] [78] [82] [217] [218] [219]. The research utilized mixed methods, which is particularly beneficial to evaluate complex interventions and analyze the outcomes, and supports the efficacy of the results as they are presented in both numbers (measured performance) and words (appropriateness).

6.3 Weaknesses of the study

In Frederikshavn region, there were not enough participants to comprise both the test and control groups, so it was decided that the recruited participants would all be in the test group. It was difficult to recruit at least 10 test and 10 control participants in each region, and it was decided that highest priority should go to filling the test group. This meant that the study was quasi-experimental. Initially, the exclusion criteria excluded participants who have dementia secondary to head trauma and those who are bedbound (confined to a bed or chair for 20 hours a day for 4 out of 7 days). In the Denmark region, one participant was interested who was both bedbound (in a wheelchair) and suffered cognitive impairment secondary to a head trauma (due to a fishing industry accident). This participant was discussed within the project consortium, and it was determined that they could remain in the clinical trial as the primary outcomes to be measured in the trial were the evaluation of the gerontechnology devices and services and any related effects on QOL, which could still be measured in this participant dyad [275]. It should be noted that not all participants had a medical diagnosis of dementia and accompanying stage, as many were referred by professionals or relatives who noted cognitive impairment or probable dementia. It was a significant difficulty in the research project to recruit participants in the early stages of dementia since many of the formal health care organizations are first brought into care management when dementia is more pronounced and causing noticeable hindrances [275]. Additionally, there were some participants whose cognitive functioning scores ranged outside the inclusion criteria of 9-26. In the intervention group, three participants had MSME higher than 26, and seven had MMSE scores higher than 26 in the control group.

- It is possible that the test and control groups of participants in the study were not equivalent to start with, so outliers in either group could distort the results. In fact, it is assumed to a certain extent that the two groups of participants are not equivalent as would be in most randomized-controlled trials. It is well known that no two individuals with dementia will experience the syndrome equally and there is essentially nothing to compare the rate of decline to; the heterogeneity of the populations (those with dementia and their caregivers) makes generalizing resultschallenging . This was a known risk to the internal validity of the research design. When comparing control and intervention groups in dementia care, the following are considered:Comparing test and control groups is not in itself a demonstration of validity.
- The technology services can only help with some of the unmet needs of the test group, as the care situation is multifaceted.
- It is not possible to directly correlate institutional placement during the course of the trials (i.e. participants who withdrew) to the use or non-use of the gerontechnology.
- Some of the differing results between the test and control group may not be explained by or ascribed to the gerontechnology intervention.
    - In particular, frequent visits to the participants due to installations, technical problems, and for assessments may inadvertently influence their QOL, which is unrelated to the use of the gerontechnology services.
    - Likewise, some of the system's technical issues may inadvertently cause distress among the test participants.
    - Changes in cognition cannot be explained by the technology intervention alone.

The European Economic Crisis was another major setback that was encountered. Specifically, the public sector halted to a standstill in Trikala, Greece for six months. This put a hold on recruiting professionals (psychologists) and thus recruiting participants, which delayed the starting date in that region. This was also the region with the lowest mean length of use (μ=137 days compared to total test group, μ=192,45). In Northern Ireland and in Greece, some potential participants lived in the mountains where internet connectivity was not adequate to support the gerontechnology system. Unfortunately, these participants could not continue with the project as intended and either withdrew or were assigned to the region's control group. Furthermore, some participants who were able to continue with the project lived in regions with low coverage that caused internet stability issues during the testing period which impeded SW updating and caused some concern for the participants (i.e. worry about system and service credibility). Working in multidisciplinary teams posed difficulties, particularly in communicating technical problems between the (social and health care) regional partners and the technical partners. The formal caregivers expressed challenges in explaining the user's problems to the technical partners or in attempting to simulate the problems encountered. It took some months for the consortium to find a simpler, common language that all could understand. However, once this was achieved, all partners had a better understanding of what was expected and what could be delivered through technical solutions.

Similar to previous research, this study also has methodological problems, and this study did not attain minimal systematic error. There were instrument and administration errors, and more visits to the home due to technical problems and additional training than anticipated. This study also did not attain a high statistical power. Having n=40 participants per group would have given 80% power, however this analysis has n=53 participants, attaining a power of 35% when testing the hypothesis between groups. Furthermore, as this is a non-equivalent comparison, the possible effects are considered. Although there were no significant differences between the intervention and control group assessment scores at baseline (including cognition scores), there are some distinctions which may be influential. The control group caregivers were an average of 8,97, years older (p=0,02**), and the majority were spouses. Middle-aged caregivers are most likely to be caring for both their parents and their children, i.e. the sandwich generation, which might explain the (non-significant) higher baseline ZBI when compared to the control group. Caregivers with high levels of burden are more likely to seek out formal support services [76], which may also be a factor in joining the study. Younger caregivers, who are typically higher users of advanced technology, may also be more interested in joining the project [79]. Since, caregivers in the intervention group may have exhibited self-selection bias in participating due to higher levels of caregiver burden and/or an interest in technology to support care, causation is difficult to determine. Though certainly a difference between the sample populations, this is still considered acceptable as the average caregiver is an adult female relative of the person with dementia, and both wives and daughters are identified as high risk subgroups for experiencing caregiver burden [78] [217]. In order for a strong conclusion to be drawn on this outcome, the quality of the research needs to be strong:

1. The difference in caregiver burden must not be before the intervention. The results show there is not a significant difference in any of the assessments at baseline.
2. The highly significant difference in caregiver burden is related to the intervention. The results show that the improvement in burden is not correlated to any other variable and cannot otherwise be explained by the data.
3. There are no other confounding variables that could explain the difference in caregiver burden. The results show that age and length of use may be confounding variables. Declines in IADL did not have a significant correlation with declines in ZBI.

6.4 Future directions in dementia care

Smart Homes have the capability to minimize risks to physical safety and assist with daily activities. When coupled with care services, like Ambient Assisted Living , Smart Homes also promote healthy, independent living, and can collect information on user patterns to adapt the home environment. Although these types of advanced technological systems are not extensively used in present day, the continued advancement of technology and its assimilation into society calls for some speculation on what the future of personalized dementia care could look like.

There are a range of technologies that have already been developed or are near-ready for public markets [10], such as accelerometers that can predict falls before they occur [323], and gait sensors that can recommend rehabilitation strategies to prevent falls [324]. Smart materials can collect biosignals via surfaces in the home or materials worn by the user [325], and affective computing can identify and process fluctuations in human emotions [326]; recognizing variations in affect and communication patterns could allow behavioral expressions to be distinguished from cognitive distress or symptoms of comorbid conditions (e.g. pain). Likewise, advances in the field of robotics are making great strides in incorporating affective computing so that the robots can detect human expressions through facial and body language and will have the capability to adapt to the individual's mood [327]. Furthermore, improvements in personal and microcomputers, such as wearable technologies, and embedded bio-sensing devices, will extend the user-defined context outside of the home environment. Devices increasingly connected to each other through ICT will allow communication over mobile ad hoc (MANET) and mesh networks, as envisioned through the Internet of Things (IOT), enabling individuals to interact with their community in new ways (i.e. Smart Cities). For more future perspectives of technology in dementia care, please see Paper F.

Previously, loss was a fundamental theme in many aging theories. It seems that much of the research on dementia caregiving postulates a similar negative curve, given that burden tends to increase as functioning declines. People are more than the sum of their roles: as the person with dementia is more than their impairment, just because dementia caregivers experience of burden does not mean that is all they experience from caregiving. Perhaps, as there is this paradox of aging, there too is a paradox of caregiving. Although the majority of the research on caregiving focuses on the negative aspects, there are some studies which report the positive aspects [77] [78] [328]. Up to 90% of caregivers report positive feelings were cultivated by the act of showing care and support, improved relationships, togetherness, sharing activities, opportunity to show love, reciprocated bonds in the care dyad, feelings of accomplishment, mastery, and personal and spiritual growth. This implicates that caregiving, for many, is a means to continued growth and development. It is feasible that caregivers can be supported through co-creating and tailoring the telecare, but can be further supported by enhancing the methods they already find effective. Caregivers are also aging individuals, and gerontology asserts that aging involves using knowledge and tools to control and adapt an environment, or to adapt to an environment. It would be interesting research to test if gerontechnology interventions aimed at declining behaviors (e.g. wandering) have different benefits than interventions aimed at coping behaviors (e.g. task-focused, or emotion-focused coping) [218] [328], or could integrate the two.

The background discussion on diagnosing dementia emphasized a disconnect between the trends in early diagnosis and the critical requirement of accurate testing. After searching the literature, conducting the research, and describing the results, it appears there is also a disconnect between the trends in gerontechnology use in dementia care and the essential understanding of significant, validated benefits. Exponential growth tells us that technology advancements will continue, and at an increasing pace. This will benefit both diagnosing dementias and developing technologies that support the safety and well-being of people with dementia. It will be more beneficial to consider what the future of dementia care could be, and influence development based on what gerontologists do know about living with dementia and caregiving for someone with dementia. This has vast implications in dementia care, as the number of trained caregivers decreasing; technology-supported care could greatly complement the demand for intuitive, personalized care. Sensors, cameras, social media content, and affective computing, could allow for the early detection of dementia by identifying symptoms through patterns of behavior in individuals. This also suggests that the individual could exercise more independence in utilizing community services such as local parks or grocery markets, as pervasive computing could detect the location, gait, etc. of the person, and contact a designated authority if a hazardous situation arises. Cloud computing will provide Internet-based services that can be accessed globally, essentially making computing a public service, and will enhance health and social care provision through, e.g. secure transfer of medical history among care professionals, or allowing a person with dementia to take holiday with uninterrupted care services. Having immense amounts of data transferred through the cloud also provides an avenue for complex analysis of large data repositories. When (anonymous) health data is collected, a wealth of information can be analyzed and used to further enhance services. Utilizing Big Data analysis can improve the quality of health care as well as improve decision making through evidence-based medicine, which in turn provides an evidence base for policy. This is timely as the World Health Organization issued a report in 2012, urging the development of dementia plans that parallel searching for a treatment or cure with advancing evidence-based quality care [33]. These more recent advances do not have widespread use as of yet, largely due to major issues in data storage and security, system architecture, and service provision management. But they are on the horizon, and beginning a discourse on future trends in dementia care will highlight ambitions and contribute to setting goals for the future of dementia care services and evaluations. With a growing ability to optimize healthcare, advancements in technology will allow for both monitoring and treating in real-time, at the point of care [200]. The ambition is that health technology assessment will be as advanced as the technologies it is evaluating.

In this study, caregivers noticed that the reminder service became less useful as cognition declined, and an interesting area of future research would be in the cognitive thresholds for using interactive services, such as reminders. This information would be beneficial for clinicians and caregivers as well as for the technical partners, who need well-defined user requirements. Another area of gerontechnology research that would be beneficial is in the use behaviors of caregivers checking the telecare portal (e.g. frequency, duration, type of information accessed). The success of future research projects in this area can be enriched through educating and training professional caregivers on research methods and the study design. This will help the caregivers to better identify information that is useful to the research and to recognize research outcomes that are useful to their profession. A deeper discussion on the outcomes for caregivers and the relevance for individuals, health and care providers, and policy makers can be found in Paper G.

A substantial criticism when evaluating technology interventions in dementia care is that reliable conclusions are difficult to realize. This is often attributed to the challenges in collecting and interpreting data in a unified way (with many studies reporting anecdotal evidence), obtaining large enough sample populations, and due to the dementia and intervention outcomes being highly individualized. Another major impediment to assistive technology evaluation in dementia care is the lack of standardized ontology. Developing, utilizing, and evaluating technologies for dementia care involves the collaboration of engineers, health and social care professionals, citizens, psychologists, gerontologists, etc. Without a common language to describe the technical components and classify outcomes, it is difficult for multiple levels of professionals and users to comprehend the full scope. Furthermore, as the law of accelerating returns continues to be a force, it will become increasingly challenging to incorporate the expanded development in technological solutions. To date, there are no quality of life assessment tools that are dementia-specific and incorporate technologies as either as an influential aspect nor a mode to administer the assessment. Having a computerized procedure for evaluating telecare systems' effects on end users (i.e. QOL), could facilitate drawing reliable conclusions by collecting and interpreting data in a unified way and allowing this to take place longitudinally and at the point of care.

The analysis of the standardized assessment outcomes does not provide evidence that using technologies directly increases the quality of life of the older adults with dementia. However, one could start to speculate that improving the conditions and life quality of caregivers could have an effect on the individuals with dementia. As well, the benefit of assisting the caregivers in their tasks shows promise for future developments to meet the projected growing demand for dementia care. The responses to the additional questions show support for the hypothesis, that using technology in dementia care will have positive effects on quality of life. Since these responses were to global questions regarding feeling of change for quality of life, further investigation into how the participants define their life quality and how they feel the technology had improved life quality would be valuable research. The caregivers in the ISISEMD study perceived more positive outcomes than the standardized assessments captured, and it is likely that there are outcomes that could be measured more effectively than through physical functioning and burden. Future research into how participants arrive at their global conclusions, perhaps even allowing them to discuss the difference in outcomes they present in quantitative and qualitative, would provide a great amount of information on dementia care interventions and the relative usefulness. However, it is cautioned to keep the number of questionnaires to a minimum in order to avoid overloading the participants, and to carefully consider the psychological effects of the questions in the assessments. Understanding how the end users define and perceive their life quality would not only benefit the conceptualization of quality of life in dementia care, but provide some domains to integrate into the development of services. This would help to develop services that are meaningful to the end users as well as to target interventions to areas of quality of life to be enhanced.

Discussion summary

The study successfully implemented and tested the telecare services in 4 European countries for over a year. The services were tested in real-life conditions and were tailored to accommodate the different organizational structures of care and the individual adults using the interventions. 7 standardized evaluation tools were used to assess the quality of life of the end users in both groups and the intervention group answered additional questions through non-standardized assessments of their acceptance and satisfaction with the system and services. Since quality of life has no gold standard to compare against, it was hypothesized that the range of assessments could provide a multifaceted portrayal of the effects on overall quality of life. The assessment tools evaluate a set number of indicators and looking at domains that are measured can provide a comparison for the changes which may be influenced by the technology. It should be considered that lengthy administration of the evaluations can cause stress and fatigue, and administration methods can increases the risk of carryover and order effects and interviewer bias. It was challenging to attain the required number of participants and the Denmark region did not have a comparative control group, presenting a risk to the internal validity of the research. Furthermore, one dyad was allowed to participate despite meeting exclusion criteria and some participants were switched from the intervention group to the control group when it was discovered that they lived in areas where internet-based services were not feasible. There were also more visits to the homes due to technical problems and more training than anticipated, which could have unintentionally influenced the outcomes. Multidisciplinary teams provided the advantage of sharing expertise across technical, governmental, social care, medical, and academic fields. Particularly in the first part of the project, formal caregivers found it challenging to explain or demonstrate the user's problems to the technical partners. After several months, the consortium found a mix of professional languages where all could understand what was expected and what could be delivered through technical solutions. Overall, the ISISEMD project was an ambitious undertaking to create and implement a functional telecare system and evaluate quality of life outcomes in a span of 30 months. More challenges were faced than expected (both in regards to the technology and to the human aspects), and several tasks were more time- and resource-demanding than anticipated. In the pilot, the technical system achieved acceptable immediacy (alarms were triggered automatically), discretion (sending notifications to appropriate level of help, only immediate alarms are sent by text message), and flexibility (all services can be activated or deactivated, personalization of services).

Several important differences in the IADL, SQLC, and ZBI instruments were identified during the research that have not previously been reported in the literature, and it is hoped that continued use and development in this area will provide stronger evaluation tools in the future. Although the gerontechnology intervention was well-received by the participants, the statistical analysis shows that the intervention did not have a significantly different effect than usual care. The qualitative feedback does not appear to reflect the quantitative results, which leaves doubts about the methods and their ability to detect meaningful outcomes. It is possible that the constructs that are measured are not influenced by the technology as hypothesized or that latent variables are influencing quality of life more than the intervention. Another explanation could be in the nature of determining the (clinical) significance of non-pharmacological and palliative interventions, especially as one technological device or service could serve multiple meanings to one person, and this will often vary between persons. Research in QOL is faced with the theoretical challenge of whether *quality of life* is considered a reliable and valid measure of the actual construct. Particularly when researching interventions for the care of chronic and degenerative conditions, consideration should be paid to evaluating not only negative outcomes (e.g. problem behaviors, burden, depression) but also positive outcomes (e.g. sharing activities, feelings of accomplishment, reciprocated bonding). This would provide a more holistic view of the situation and, therefore, possibly QOL as well as provide information on enhancing methods and outcomes that the dyad already find to be beneficial.

There appears to be a disconnect between the advance in early detection and diagnosis of dementias and the essential requirement of accurate testing and appropriate treatments. There also appears to be a disconnect between the use of gerontechnology in dementia care and the support of significant, validated, benefits. As with most treatments and interventions for dementia, gerontechnology appears to have marginal positive effects. Exponential growth tells us that technology advancements will continue to benefit both diagnosing dementias and developing technologies that support the safety and well-being of people with dementia. Ambient Assisted Living and Smart Homes can promote healthy, independent living, and collect information on user patterns to adapt the home environment. Personalized devices that are increasingly connected to each other through ICT will enable individuals to interact with their community in new ways (i.e. Smart Cities, Cloud Computing, and wearable technologies). This is an exciting time in gerontechnology, and gerontologists are needed to envision and discuss future trends in dementia care, and to identify ambitions and set goals to influence the development of these services.

Key results:

The comparative analysis shows a significant difference in caregiver burden between the caregivers. All of the dyads who show increases in caregiver burden (ZBI) also show significant declines in independent functioning (IADL). The control group shows a highly significant increase in caregiver burden and the intervention group shows a non-significant reduction in caregiver burden. This indicates that the technology intervention has positive effects on quality of life through reducing or preventing a significant increase in caregiver burden. Aside from protective effects in caregiver burden, the technology-supported care and usual care do not show significant differences in their outcomes.

What this study adds:

- Evaluation tools need more development
    - Current tests may not be measuring what is being affected by the intervention or what is important to quality of life. Both broad and specific research and development is need on QOL and dementia care outcomes are needed.
- Conceptualization of QOL is necessary in order to compare results.
- Technology is changing faster than research methods. It is advisable that gerontechnologists also contribute to standards and legislation (privacy and security) and public health (provision and access to services) in order to envision where and how gerontechnology capabilities will develop.

Papers supporting Chapter 6:

Paper D supports the discussion by giving the results of the mid-term evaluation and describing changes to the methodology from the original study plan. Paper F considers future prospects of using technology in dementia care, supporting the discussion on future directions in this area of research. Paper G contains the literature search for comparable ZBI outcomes and an expanded consideration of the clinical significance of outcomes in caregiver burden, including the relevance to individuals, care providers, and policy makers. Paper H describes the specific differences in the SQLC tool across the regions.

Chapter 7. Conclusions drawn from the research

Indeed, assessing quality of life is complex and poses some serious conceptual and methodology issues. Is “quality of life” a meaningless term? It does not appear so; in fact, it seems to have many definitions and even more meanings. Perhaps multiple conceptualizations are useful as they would allow the concept to be measured across different levels of human experience. The notoriously elusive definition could change from the micro to the macro level, from children to advanced old age, from healthy humans to those with specific maladies. It could be discipline-specific, population-specific, or role-based in its meaning. Perhaps it is best to be determined by utility: is the goal of assessing quality of life to predict, inform, or compare. This study used quality of life to compare between similar groups, meaning that the concept of QOL was role-based and serves as a comparison outcome.

The conclusions in Chapter 7 associate this research to the wider sphere of application, rationalizing that even though this area of research is theoretically and practically challenging, the fact is that technology is becoming ever ubiquitous and the exponential growth of its application to health and social care warrants the development of efficient, cohesive methods for measuring and interpreting the implications of its use. The appendices contain auxiliary information, comprised of details from the background investigation, the questionnaires used in the research, papers that are included as part of the thesis, and supplementary data from the statistical analysis.

Without homogeny in the field of QOL research, comparing results across studies is difficult and conclusions drawn from comparisons are often consistent only to an extent. There are few studies that were long-term, real-life testing of technologies for dementia care. Those that do examine the relationship between technology use and care outcomes often consider a specific type of intervention, i.e. occupational or cognitive-behavioral therapy, and not necessarily a specific type of technology. It seems that many of the assisting technologies and telecare services are aimed at accommodating for functional declines. If the full spectrum of the self-reported QOL domains from individuals with dementia is to be applied in future research, there are several domains that are not explicitly addressed in the evaluation tools. As discussed in the theory section, activity theory draws a positive correlation between activity and life quality, which reduces QOL to a range of activities and neglects to explain how the paradox of aging could exist for adults with dementia. Human experience consists of more than quantitative results and further development in assessment methodologies is needed to be able to portray a more realistic situation. At the same time, the majority of ATs are directed towards the physical care needs, such as the basic and instrumental activities of daily living. True, these are important aspects of care and certainly an area where technology can be tailored to fit the requirements of the user, but addressing physical care needs is only touching a portion of the domains of quality of life. Investigating the enrichment of (person-centered) life quality and the (biomedical and psychosocial) management of decline expands the evidence base and ensures that the intervention addresses the unique, individual psychosocial issues as well as physical and mental health. Furthermore, this supports that research efforts are focused on interventions that are effective for individuals with dementia and their caregivers to receive appropriate services that they are motivated to utilize. Studies on quality of life in this population have yet to separate from activity theory, as many assessment tools use engagement in activities as markers indicative of life quality. With the accelerated advancement of technology, those who develop health technologies could serve their patient populations by also integrating the psychosocial user requirements and addressing the domains identified as influential. It is complicated, arduous work, which most likely takes years to realize, but it is a worthy goal to develop services that also address attachment to place, feelings of usefulness, and self-image. There are possibly better tools to use and better methods for such research, and the continued development will be exciting.

This thesis focused on the quantitative results of testing the effects on quality of life from technology interaction in dementia care in order to add to the evidence base. In order to build confidence in the external validity of the results, the variables have been defined, the standardized tools are acceptable to measure the constructs, the methods are appropriate for the type of research, the results are applicable within their stated ranges, the effectiveness of the intervention is reported through quantitative results, the usefulness of the intervention is reported through qualitative results, and the theoretical analysis allows for analytic interpretation. Similar to previous research on technologies in dementia care, this study is hampered by methodology weaknesses. Although research in this area is known to be complex and unpredictable, other researchers could learn from the methodology and technical setbacks that ISISEMD experienced. There is evidence of performance validity that the intervention would be comparably useful in some similar cases. The telecare intervention was perceived as useful, and the overall non-significant difference in outcomes also means that the gerontechnology is not less effective than usual care. There is not strong evidence to reject the null hypothesis, and, based on the threats to the internal validity, the relationship between gerontechnology use and the positive effects in caregiver burden are cautiously interpreted from the data.

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Appendix 1 Papers

This thesis has been submitted for assessment in partial fulfillment of the PhD degree. The thesis is supported by scientific papers and parts of the papers are used in the thesis. Co-author statements are available to the assessment committee and to the Faculty. The papers have been reformatted to fit the style of the thesis. Coauthor agreements of the PhD student's contribution are included.

Papers included in Chapter 2:

Paper A supports the background by providing a discussion on theories used to understand older adults' experiences of interacting with technology and Paper B discusses the background work on quality of life studies and identifies influential domains of QOL for individuals with dementia. Paper F present a description and discussion of research projects focused on gerontechnology. Paper D offers a discussion on instrumental work in quality of life studies, environment as a mediator for activity, and theoretical motives for the interventions. Paper E also describes a search for quality of life measurement tools. Paper F considers the accelerated co-development of technology and society and the opportunity for technologies to support people with dementia.

Papers included in Chapter 4:

Paper B supports this chapter by discussing a prototype for an electronic quality of life assessment for use in dementia care. Paper D describes the ISISEMD development, implementation, and evaluation methods, and by explaining the services. This paper also describes baseline and intermediate results of the trial. Paper E reports a literature search for dementia-specific quality of life assessment tools that could be used to evaluate telecare impact. This paper also considers revisions to the proposed electronic QOL assessment prototype. Paper F presents a cutting-edge description of gerontechnology use, evaluation, and continued development that is accelerated through advancements in technology, indicating a need for electronic QOL assessment methods. Papers G and H additionally describe the ISISEMD methodology.

Papers included in Chapter 5:

More information on the outcomes from the project can be found in Paper D, Paper E, Paper G, Paper H, and in ISISEMD project reports. Paper D presents results up to the mid-term evaluation of the ISISMD project and includes qualitative information from the participants. Paper E presents outcomes as well as lessons learned from the research project. Paper G specifically addresses the outcomes in caregiver burden, including qualitative information, and Paper H focuses on outcomes for caregiver quality of life.

Papers included in Chapter 6:

Paper D supports the discussion by giving the results of the mid-term evaluation and describing changes to the methodology from the original study plan. Paper F considers future prospects of using technology in dementia care, supporting the discussion on future directions in this area of research. Paper G contains the literature search for comparable ZBI outcomes and an expanded consideration of the clinical significance of outcomes in caregiver burden, including the relevance to individuals, care providers, and policy makers. Paper H describes the specific differences in the SQLC tool across the regions.

Paper A: The phenomenological experience of dementia and user interface development

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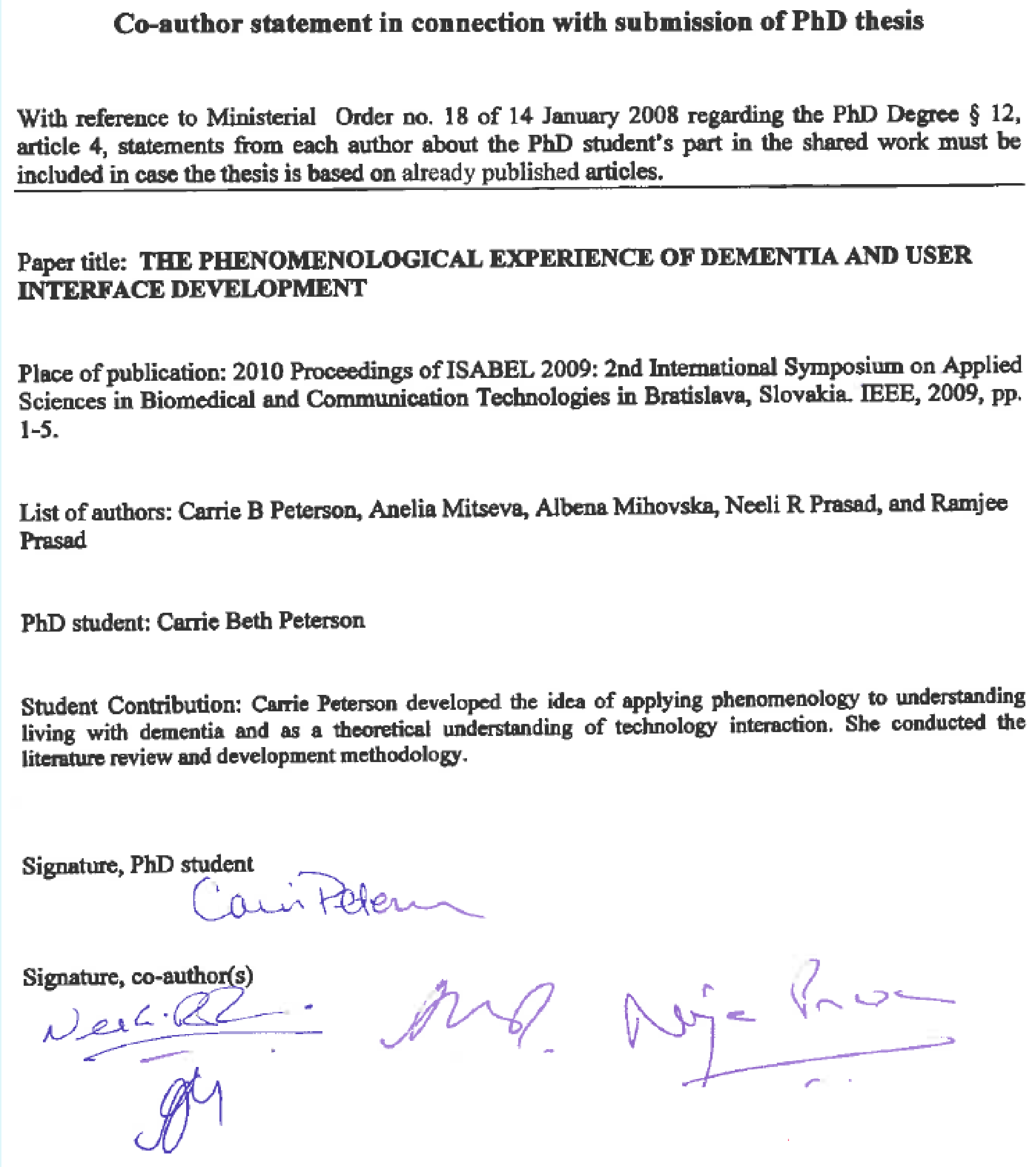
Abstract— This study follows ISISEMD through a phenomenological approach of investigating the experience of the Human Computer Interaction (HCI) for someone with dementia. The aim is to accentuate the Assistive Technology (AT) from the end user perspective. This paper supports that older adults and those with dementia should no longer be an overlooked population and how the HCI community can learn from their experiences to develop methods and design interfaces which truly benefit their target population. Guidelines from previous research are incorporated along with eclectic, user-centered strategies as the interface designers for project ISISEMD develop appropriate and effective modalities.



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **THE PHENOMENOLOGICAL EXPERIENCE OF DEMENTIA AND USER INTERFACE DEVELOPMENT**

Place of publication: 2010 Proceedings of ISABEL 2009: 2nd International Symposium on Applied Sciences in Biomedical and Communication Technologies in Bratislava, Slovakia. IEEE, 2009, pp. 1-5.

List of authors: Carrie B Peterson, Anelia Mitseva, Albena Mihovska, Neeli R Prasad, and Ramjee Prasad

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson developed the idea of applying phenomenology to understanding living with dementia and as a theoretical understanding of technology interaction. She conducted the literature review and development methodology.

Signature, PhD student

Carrie Peterson

Signature, co-author(s)

Paper B: Framework for dementia quality of life assessment with assistive technology

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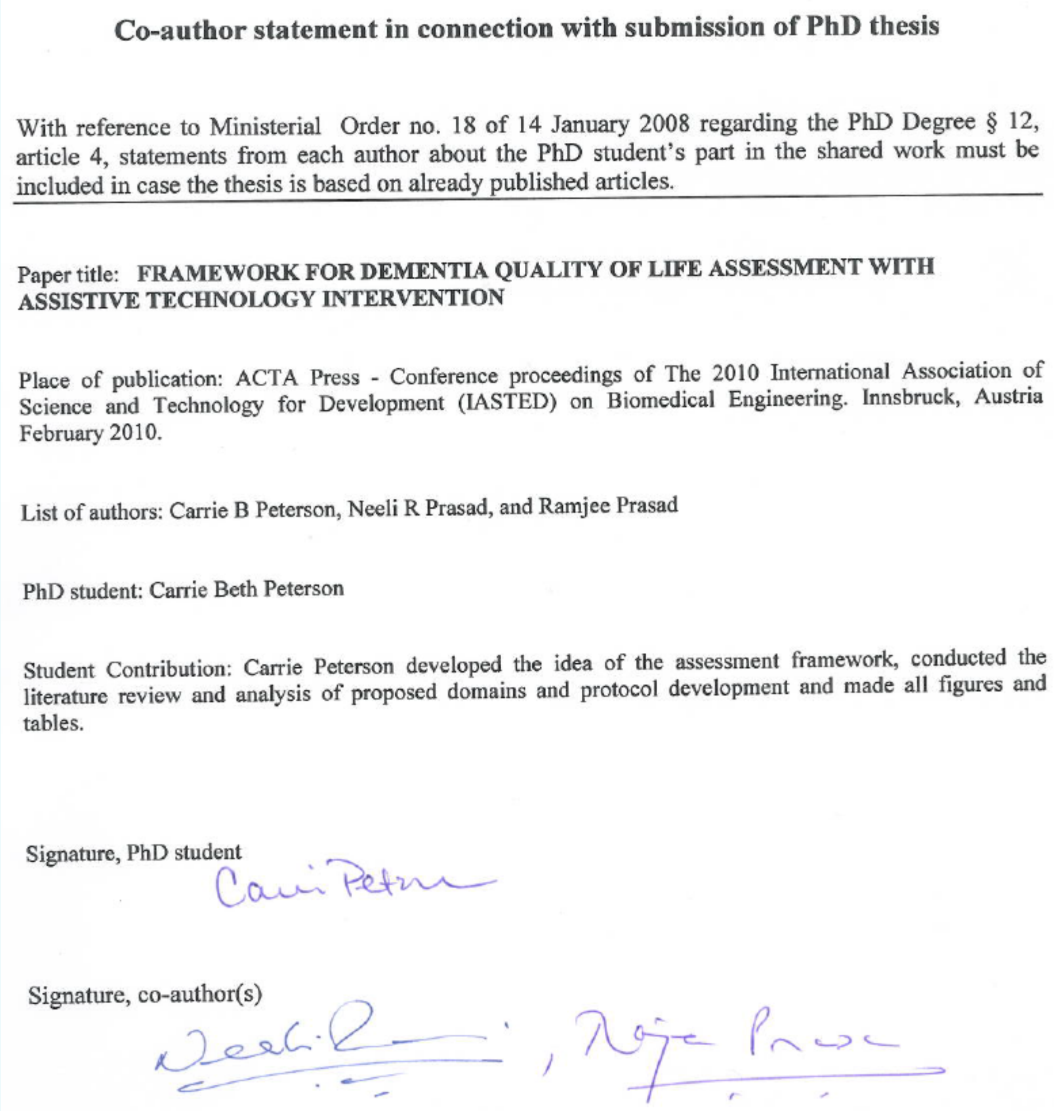
ABSTRACT

This paper proposes a theoretical framework for a Quality of Life (QOL) evaluation tool that is sensitive, flexible, computerized, and specific to assistive technology (AT) for dementia care. Using the appropriate evaluation tool serves to improve methodologies that are used for AT assessment, development and improves the understanding of how health technology outcomes affect overall care. It will largely serve to develop the competence of technology assessments through a more efficient procedure for evaluation. One of the many challenges to assessing QOL is that results are subjective and difficult to analyze in an objective, empirical manner. This paper accentuates that this is not a hindrance to measuring OQL, but could be emphasized and adapted to create a precise measurement tool; the end-user voice must be sought and empowered in determining functional definitions and indicators for QOL. Current QOL measures inspired recommendations for a future assessment tool in order to assist investigators and clinicians in selecting the optimal method for their needs. The proposed framework is evaluated by means of a theoretical analysis focused on future applications, with particular regard to the influx in assistive technologies and their implications as therapeutic interventions for dementia care.



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **FRAMEWORK FOR DEMENTIA QUALITY OF LIFE ASSESSMENT WITH ASSISTIVE TECHNOLOGY INTERVENTION**

Place of publication: ACTA Press - Conference proceedings of The 2010 International Association of Science and Technology for Development (IASTED) on Biomedical Engineering. Innsbruck, Austria February 2010.

List of authors: Carrie B Peterson, Neeli R Prasad, and Ramjee Prasad

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson developed the idea of the assessment framework, conducted the literature review and analysis of proposed domains and protocol development and made all figures and tables.

Signature, PhD student

Signature, co-author(s)

Paper C: Easy Life, Intelligent Systems, and LIFE 2.0: European research on ICT for aging adults

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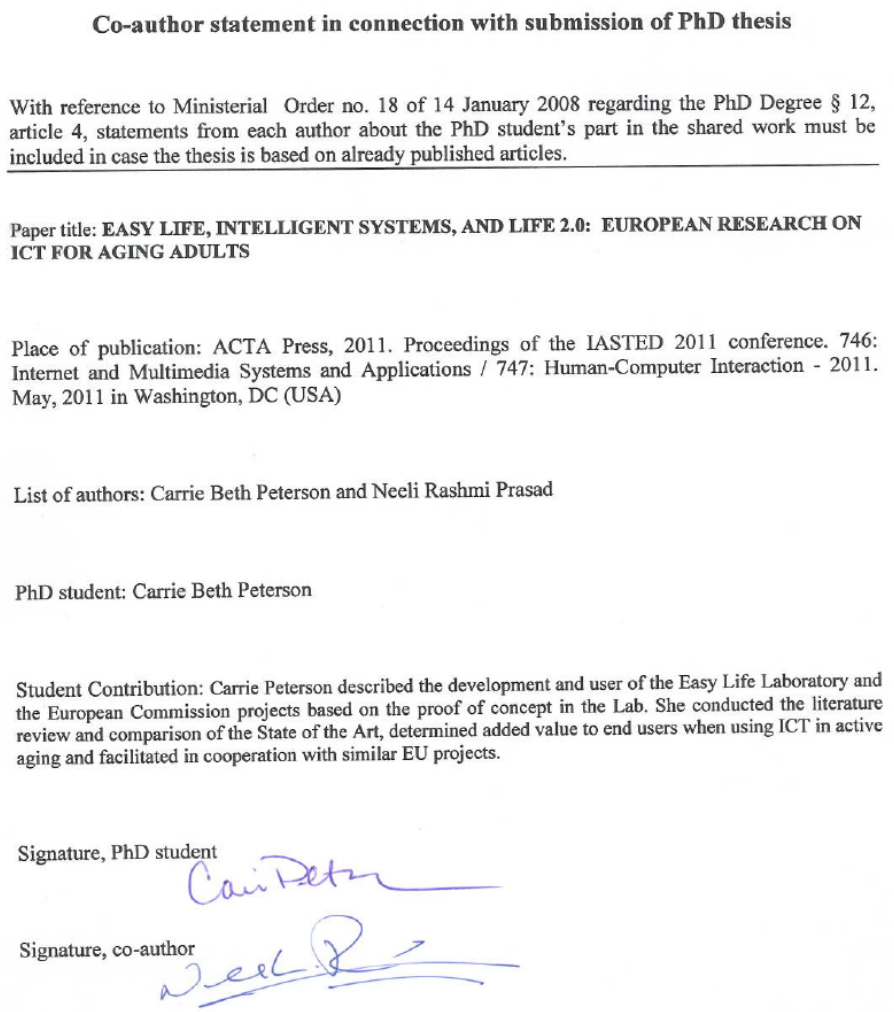
ABSTRACT

Lack of access and accessibility have been two of the largest impediments for older adults and Information and Communication Technology (ICT) use, resulting in reduced computer skills, lack of motivation, and aversion to new technologies. By looking at these influential barriers, we can see that this is partially due to technologies being designed and marketed towards the younger generations and do not allow for inclusive design. Aging is usually not considered when designing mainstream products and there can be a distinct lack of industry awareness about the cohort's capabilities. Additionally, even when Assistive Technologies (AT) are developed specifically to help marginalized groups, a lack of interoperability can hamper uptake.

Since the 1990's, the European Union has contributed to the development of eHealth and this has helped to place Europe as one of the leading world investors in the field. As a result, the EU is utilizing industrial, scientific, and social resources to accelerate product and service synchronization. Innovation and development in these areas not only benefits European citizens and residents, but also strengthens the European industry market.

ICT sectors are experiencing a growth in the needs and marketability of tools and services designed specifically for older adults. If a service is offering opportunities to emphasize resources and capabilities already available, research must incorporate design and functionality requirements and preferences of aging adults. This can help to improve or maintain QoL, allow for aging in place and independent living, increase socialization through connection services, and reduce cost of care burdens expected with the increase in aged proportions of global populations.



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **EASY LIFE, INTELLIGENT SYSTEMS, AND LIFE 2.0: EUROPEAN RESEARCH ON ICT FOR AGING ADULTS**

Place of publication: ACTA Press, 2011. Proceedings of the IASTED 2011 conference. 746: Internet and Multimedia Systems and Applications / 747: Human-Computer Interaction - 2011. May, 2011 in Washington, DC (USA)

List of authors: Carrie Beth Peterson and Neeli Rashmi Prasad

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson described the development and user of the Easy Life Laboratory and the European Commission projects based on the proof of concept in the Lab. She conducted the literature review and comparison of the State of the Art, determined added value to end users when using ICT in active aging and facilitated in cooperation with similar EU projects.

Signature, PhD student

Signature, co-author

Paper D: Gerontechnology: Providing a helping hand when caring for cognitively impaired older adults – intermediate results from a controlled study on the satisfaction and acceptance of informal caregivers

Hindawi Publishing Corporation
Current Gerontology and Geriatrics Research
Volume 2012, Article ID 401705, 19 pages
doi:10.1155/2012/401705
Clinical Study

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Received 31 May 2011; Revised 5 November 2011; Accepted 17 November 2011
Academic Editor: Ann L. Gruber-Baldini

The incidence of cognitive impairment in older age is increasing, as is the number of cognitively impaired older adults living in their own homes. Due to lack of social care resources for these adults and their desires to remain in their own homes and live as independently as possible, research shows that the current standard care provisions are inadequate. Promising opportunities exist in using home assistive technology services to foster healthy aging and to realize the unmet needs of these groups of citizens in a user-centered manner. ISISEMD project has designed, implemented, verified, and assessed an assistive technology platform of personalized home care (telecare) for the elderly with cognitive impairments and their caregivers by offering intelligent home support services. Regions from four European countries have carried out long-term pilot-controlled study in real-life conditions. This paper presents the outcomes from intermediate evaluations pertaining to user satisfaction with the system, acceptance of the technology and the services, and quality of life outcomes as a result of utilizing the services.

1. Introduction

Dementia is a group of syndromes associated with a loss of memory and other intellectual functions that are serious enough to interfere with daily task performance. There are around 40 types, or causes, of dementia, the most widely known being Alzheimer's disease. Dementia is commonly associated with aging as the risk for exhibiting symptoms of dementia increases with age, nearly doubling every 5 years after the age of 60. The chances of having dementia over the age of 65 are one in 50 and that increases to one in 5 for those over 80 years and up to 50% in adults over age 85 [1, 2]. Mild cognitive impairment (MCI or CI) is closely related to dementias. Plassman, et al. [3] found in their follow-up study that of their participants who had CI and no dementia, nearly 12% advanced to dementia annually. Although MCI is often viewed as a precursor to developing dementia, the relationship is not fully understood.

With advancements in medicine, economy, and technology, the human lifespan has increased significantly over the last decades; additionally, dementia rates have increased [4] and this poses questions about the *quality* of extended years of life. In the context of ISISEMD project, we use quality of life (QOL) to mean "the individual's perception and evaluation of the impact that the disease and its consequences have produced in their lives" [5]. As there is no cure for dementia and current treatments serve only to reduce the debilitating effects, a major area of focus in this type of caregiving is on maintaining or increasing patient QOL and reducing care-related stress.

By and large, the majority of informal caregiving is carried out by persons (usually family members, close friends, or neighbors) who have not had any formal training in caregiving and do not receive any economic retribution for their tasks. Both as individuals and as society as a whole, it is not possible to pay for the costs that informal caregiving mitigates from formal caregiving services. Needless to say, informal caregivers provide an invaluable service that is impossible to remunerate; they are the backbone of long-term care. To be a family caregiver for an older adult with cognitive impairment is a heavy task that comes with financial implications for the individual families as well as society, as well as the majority of the cases resulting in increased emotional and physical stress.

Aging in one's own home is a growing demand among baby boomers and the related technological solutions are market estimated at €14 Billion by 2020 [6]. The idea of *aging in place* is not a new one, yet only recently have governments and organizations started working towards incorporating appropriate solutions, one of the main modes is through information and communication technology (ICT) for aging, also known as gerontechnology. The inspiration of tele-home care is to have the home environment modified in order to meet the increasing care and safety needs and to reduce forced relocation, which often leads to transfer trauma and relocation stress syndrome. Instead of older adults selling their homes and moving into retirement communities or care institutions, home modifications allow the living environment to become user-friendly to aging adults [7]. The European Commission (EC), in collaboration with the Member States, has recently put more focus on the coming challenges of care for older adults with this type of disability living in their homes. Likewise, many governments are now focusing on ICT systems for supporting the elderly and chronically ill to live as independently as possible and to help citizens to be treated and/or cared for safely in their own homes. The European Commission has supported a Policy Support Program (PSP) pilot study exploring the use of Assistive Technologies (ATs) for the care of older adults with cognitive impairment (CI) by co-funding the ISISEMD project. ISISEMD has taken a holistic approach — examining and meeting the needs of the elder/caregiver dyad as a whole. Project ISISEMD (intelligent system for independent living and self-care of seniors with cognitive problems or mild dementia) [8] concentrates on adults over the age of 60 who have a documented history of CI and their caregivers. The project has developed and tested an innovative set of scalable technologies for the purpose of easing the caregiving and care receiving activities associated with dementia care and to have a positive effect on users' QOL. The project was 30-months in duration from March, 2009 to August, 2011, and involved 12 partners representing end-user organizations (Municipality of Frederikshavn — Elderly Care Department from Denmark, Belfast Health, and Social Care Trust from UK, Municipality of Trikala from Greece, Municipality of Lappeenranta-Health and Social Care Department from Finland), industrial organizations (Hewlett Packard-Italy, Alcatel-Lucent-Italy), SMEs (Converge ICT Solutions from Greece, Eltronic from Denmark, Socrate Medical from Italy), academia (Aalborg University from Denmark, National Technology University of Athens from Greece), and one public office (North of Denmark EU-Office from Denmark). During the first year of the project, the focus was to design, adjust, and implement the services which were installed in participants' homes during the second year. The services were tested in four European countries (Denmark, Finland, Greece, and UK) in real-life conditions and with the three main end-use groups – elderly with CI, their informal caregivers, and the formal caregivers.

ATs for dementia care in the ISISEMD project encompass a broad range of devices that currently exist on the market, from a touch screen computer and sensors to determine ambient functions such as temperature, movement, fire/smoke, cooking activity to Global Positioning Systems (GPS) to determine where a person is in real time. The aim is to use accessible technologies in a new way so that the user-friendliness and interoperability of such systems is increased. The goal of all, however, is to maintain or increase the safety of the person living with CI and to have a positive effect on the QOL of all involved.

The contribution of this paper is to present results from a controlled study carried out in real-life conditions with older adults with CI and their informal caregivers (ICGs) from four European pilot sites. Their homes were installed with the technical equipment that gives them and their informal caregivers possibility to use innovative home support services for a period of more than six months. The controlled study was carried out for 15 months, with intermediate and final evaluations. Results from the intermediate evaluations of the services are presented in this paper, with a focus on informal caregivers and from user acceptance and satisfaction of the technologies view point. Moreover, an analysis of the influence on the QOL and the stress of caregiving for the family caregivers are provided.

The rest of the paper is organized as follows: in Sections 2 and 3, we give an overview of the experience and stress of caregiving and how the ISISEMD services can help the informal caregiver and their relative with CI. In Section 4 we shortly present different aspects of the assessment methods. The main contributions in this paper are presented in Section 5—primary and secondary outcomes from intermediate evaluations for QOL, stress of caregiving and user satisfaction and acceptance of the AT services. The paper ends with discussions of the findings in Section 6 and conclusions in Section 7. As a qualitative feedback from the controlled study, the voice, and perception of test persons and their informal caregivers is presented in the appendix by "success stories" from using the home services.

2. Caregivers and Society Experience Caregiving Stress in Dementia

Individuals who have conditions resulting in chronic illness or disability often face challenges in carrying out their daily activities, such as meal preparation, bathing or transportation, which involves a considerable amount of time, devotion, perseverance, and patience to perform these tasks. In most dementia situations around the world, caregiving is carried out informally by family and friends. Statistically, the majority of ICGs are female family members and most often the middle-aged child or spouse of the person with CI [9, 10]. Assistance to the person with dementia is generally provided by a single caregiver and this responsibility lasts for an average of 5 years [11]. Caregiving is typically delivered (as long as possible) in the residence of the dependent person on a continual basis, ranging from personal safety and psychological support to physical care, such as hygiene. Members of the caregiving/supporting team determine who will provide care and in which roles and what resources are available; however, caregiving for dementia is rarely a straightforward and static arrangement. The total hours of caregiving per week can easily exceed most national standards for fulltime employment, especially in the advanced stages of the process, as the person becomes increasingly dependent and requires daily, continuous assistance. For many caregivers, the requirement of full-time help often results in a decline in the ICGs personal and professional life, ability to manage the household(s), and to perform the range of care and personal activities.

It is well documented that the caregivers of persons with dementia experience substantial stress from the caregiving tasks they perform [9] and the need for permanent care to the chronically disabled person often leads to a decrease in the QOL of caregivers [12, 13]. De Vugt et al. [14], Bauer et al. [15], and others in the field report negative effects on ICGs QOL when compared to non-caregivers. According to Deeken [16], the stressors and their resulting effects on ICGs also influence when and why ICGs seek out formal caregiving (including institutionalization). In 2008, Adams [17] reported that caregivers are more likely to experience depression, anxiety, and physical health issues when compared to non-caregivers, while also reporting less hope for the future, less happiness, less enjoyment of life and greater degrees of sadness, being bothered, and loneliness. Since CI and dementia are typically chronic in nature and there is no determined end point of the care needs, caregiving is correlated to reduced physical, psychological and social health [18]. Due to research in this area, informal caregiving is respected as a critical stress factor; this is one area of focus that ISISEMD is developing solutions for. It is not uncommon that ICGs often experience greater measurable benefits from the use of AT than those with dementia themselves. A commonly accepted theory for this phenomenon is that awareness and insight into the situation is one major factor influencing fluctuations in QOL, and where those with decreased cognition experience an increasing lack of awareness and insight, it becomes more difficult for them to assess their QOL status. Meanwhile, the ICGs (typically) maintain their awareness of the situation and thus experiences greater stress from its increasing demands as the illness progresses. Furthermore, due to the increasing stress for ICGs, they often project negative attitudes on to the elderly persons (EP) QOL and typically rate their loved one's QOL as lower than the person would rate it themselves. This may be due to evaluating EPs QOL as ICG sees it versus as how EP sees it or to anticipating that with increasing need for care, QOL will decline. The exact nature of these observations is confounded and an area of focus in gerontology and caregiving research that ISISEMD hopes to provide insight to.

It is well known that a disabled person may often disorganize the life of the family, disrupting the previous balance; it is also well known that caregivers of persons with dementia experience substantial stress from their caregiving tasks. The concept of the "burden of care" was defined by the American gerontologist Zarit in 1985 [19], as the discomfort encountered by the primary caregiver of an older family member during their caregiving duration. Caregiver burden includes the caregiver's health, psychological wellbeing, finances and social life, among others. Since 1985, there have been numerous studies demonstrating the negative impact of increased caregiver stress on the person with dementia as well as caregiver's overall health [9]. During ISISEMD project, we have observed that the term "burden" has a negative connotation and impact on the family caregivers who care for their relative because they care deeply for them and choose to carry out these activities themselves. However, as caregiving inherently causes extra stress in their everyday life and this is one of the parameters measured during the project, we use the term “stress” and not “burden” as a more accurate and respectful terminology.

By introducing ATs to the care situation, ISISEMD project aims to have a positive impact on the informal caregivers and the society as a whole; below, we list the foreseen added value for them.

Foreseen value for the ICGs as a result of using ISISEMD technology services:

i. reduction or maintenance of the level of the caregiving stress;
ii. information on the location of their EP when outdoors;
iii. interaction with the services is easy to manage and with high level of individualization, accommodating ICGs who may not have previous experience with computers, also offering initial default settings;
iv. means to communicate with EP remotely (through video service, mobile phone, or Lommy);
v. increased feeling of safety regarding the living environment of EP;
vi. increased feeling of satisfaction in caregiving responsibilities;
vii. ability to allocate more time for example personal hobbies and social activities.

Foreseen value for society as a result of using ISISEMD technology services:

i. financial diminution by saving time and expenses for traveling to and from EP home and for making telephone calls;
ii. reduced health and social care costs for the local communities;
iii. transfer of tasks between caregivers, which includes untrained ICGs to be able to perform caregiving responsibilities with enhanced or new methods;
iv. ability for the formal caregivers (FCGs) to provide better quality care and/or care for more clients as tasks become less demanding through the technology;
v. creation of business opportunities;
vi. influence on health and social care policies.

Most gerontologists understand caregiving stress to be an outcome of the caregiving situation and as being dependent upon variables presented in the situation and in the caregiving relationship. These stressors are also influenced by the coping strategies of the caregivers. As mentioned, caregiving for a cognitively impaired person, especially a family member, can be straining. It is not uncommon for such caregivers to experience physical symptoms, such as sleep deprivation, lapses in memory themselves (which can also be a sign of depression), or social isolation due to reduced hours spent on free-time activities. There are resources for caregivers, such as respite programs, but these are not accessible or acceptable in every area. They may come with an unwanted stigma or be out of the caregiving budget. These factors may also increase the stress a caregiver experiences in their role. Furthermore, when a threshold for stress is reached, negative behaviors and feelings — however unintentional they may be — can spill over into the caregiving relationship. At the family (micro)level, solutions to support caregiving tasks and health and psychosocial consequences are needed. Research on corroborating programs and services aimed at delivering knowledge, skills and support to the caregiving experience can in turn promote policies (macro level) to ease the strain of caregiving on the individuals as well as society.

3. ISISEMD Services—A Helping (Automated) Hand from Technology

The ISISEMD services are related to supervising the conditions of the home and any alarming behavior of the person with dementia. The system is nonintrusive, it yet provides a way to alert the elderly themselves as well as caregivers and emergency services if there would be an event that may pose a danger to them. The ISISEMD system is comprised of several technologies that communicate with each other and interoperate on the platform. One of the technical design goals was to utilize existing technologies (computer, GPS device, pressure, and smoke/fire sensors, etc.) and provide a way for them to interact intelligently. This increases the feasibility of introducing new technologies and services to the platform as they will be developed in the future as well as ensures that presently accessible (and affordable) equipment will not necessarily become obsolete as soon as newer technology is available, helping to reduce the costs of purchasing and maintaining the ISISEMD system. As the devices are integrated into one service platform, they operate in an automatic and intelligent manner, recognizing patterns of behavior (e.g., sleep habits and average room temperature) and noting fluctuations that may signal a change in status or potential danger. For the caregivers, this means that they can spend less time and energy worrying and “checking in” on their older adult because they will be alerted by the system when their physical interaction is required.

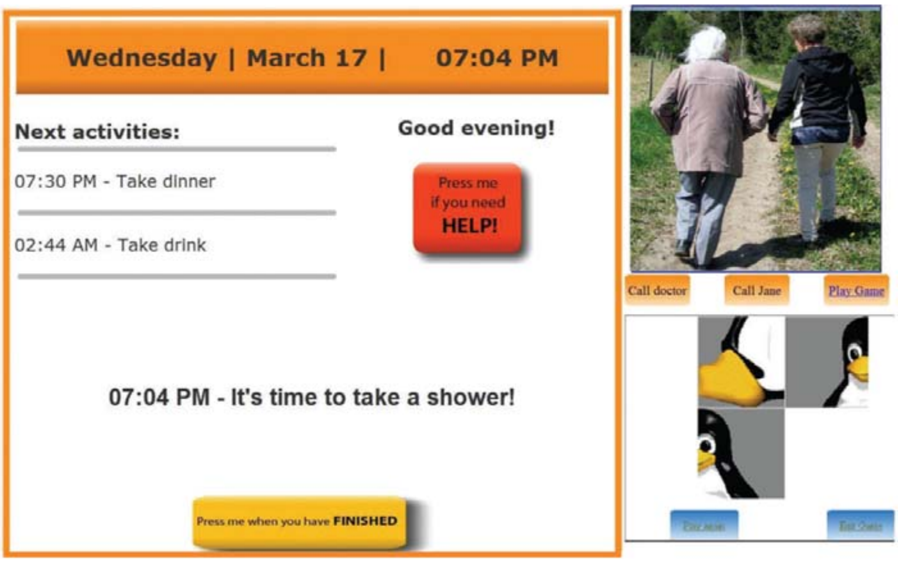
There are two categories of equipment in the ISISEMD system: *interactive devices and non-interactive devices*. The majority of the devices in the ISISEMD platform is non-interactive and includes temperature and flood sensors, smoke alarms, electricity monitors for cooking activity, pressure sensors to determine sleeping patterns, and front and fridge door sensors. The interactive devices are chosen or designed to be easy for the end-user to operate; due to the nature of the involvement being a gerontechnological system, masking the intervention was not possible and the telecare platform was visible and interactive to end users. In particular, the devices that the older adult with cognitive impairment operates require minimal interaction or no interaction at all. These include the Carebox (HP Touch Screen computer), Lommy (simple GPS device) with only one button which sends and receives phone calls, and internet connection, which is provided to the end users through the project funds. A number of the functions and services of the platform are easier to access than current mainstream technologies for people with dementia.

The *interactive devices* are those which exchange contents when prompted by the user and are under the user's control. Examples of interactive devices are for ICG-mobile phone, web portal access on a computer; for EP GPS device and a touch screen.

The *non-interactive devices* are those that, once installed by a technician, do not require any user manipulation. Examples of non-interactive devices are home automation controllers including flood detectors, and fire sensors.

The Carebox Touch Screen serves as the graphical user interface to provide information to EP at home. To accommodate different user needs, there are three levels of interaction of EP with the Carebox: no interaction at all (EP does not need to press any button, just needs to notice the screen from time to time); some interaction via "soft button" — in this case a distinct Help Button is shown on the Carebox that EP can activate; more advanced interaction — additional "soft button" for confirmation of an activity can appear or a Brain game can be played. There is also the possibility to add the Memory Lane service (picture slide show) and a video-call service. The view of the Carebox possesses a high level of flexibility and individualization, too – depending on the health status of EP, the "Help Button," the Brain games, the Memory Lane, and the video-call service may be removed from it. Figure 1 depicts the Carebox view with the highest level of interaction.

Figure 1: Screen shot of the Carebox with the Help and Confirmation button from the Reminders Service and Memory Lane and Brain Game.



Wednesday | March 17 | 07:04 PM

Next activities:

07:30 PM - Take dinner

02:44 AM - Take drink

Good evening!

07:04 PM - It's time to take a shower!

The computer of the Carebox also collects data from the sensors installed in the home and the data is sent over the Internet to the ISISEMD web portal. Following the required ethical, privacy, and security requirements, EP designates the caregivers that are allowed access to the web portal, where they can view only the information that is related to that EP. Depending on the user's preferences, the system can automatically send notifications, alerts, and alarms to ICG and FCG via SMS text messaging or email. Almost all possible aspects of the services are easy to be personalized, based on the individual, current needs of both EP and ICG. It also notifies EP via the Carebox Touch screen if there is a dangerous situation in the home.

Automatic services for EP include:

i. home and personal safety observations, such as notification if fire/smoke is detected in the home or the front door is left open or a cooking activity is going on for too long;
ii. reminders and prompts for basic daily activities such as meals and medications;
iii. predefined reminders exist but there is also the possibility to enter and show personalized "free text reminders," such as "*Marie* is coming to visit at 15:00;"
iv. locating service when the person is out of the home so that caregivers can find them if they become disoriented;
v. reality orientation by displaying the date and time on the Carebox.

Ad hoc services for EP include:

i. cognitive stimulation (Brain Games that can be played on the Carebox);
ii. reminiscence activities (Memory Lane shows a slide show with family pictures on the Carebox);
iii. video communication with caregivers at the touch of a "soft" button showing telephone image on the Carebox touch screen;
iv. automatic contact button when in the home (soft "Help" button on the Carebox touch screen);
v. automatic contact button when outside the home (red button on the Lommy device).

Automatic services for IGCs include:

i. alerts, notifications, and alarm services delivered to mobile phone or email;
ii. request for help/contact from EP when EP is in the home;
iii. request for help/contact from EP when EP is outside home, also providing information for the current EP position;
iv. alert if EP has fallen when outside home.

Ad hoc services for ICGs include:

i. through the ISISEMD web portal, ICG can see an overview of daily activities, notifications and alarms raised by the system;
ii. through the ISISEMD web portal, ICG can see an overview of activity history (lifestyle pattern);
iii. video-call service for communication with elderly;
iv. call to the Lommy device when EP is out of the home;
v. locating EP outdoor via the Lommy GPS device through the ISISEMD portal.

The following paragraphs give more details about the ISISEMD services, defining them and their role in the home care environment. In total, ISISEMD offers a possibility of 17 services, which can be selected depending on EP and ICG desires. In this way, the system can provide better support via increased care assistance which is accommodating to the progression of the dementia impairments. More technical information for the services is provided in [20].

3.1. Service Information for the Informal Caregivers

3.1.1. Scheduler.

The scheduler enables ICGs to define the parameters (time period, temperature, dangerous versus harmless behaviors, acceptable distance or time away from the home, etc.) which will activate alarms and alerts in accordance with the identified needs of individual elderly person.

3.1.2. Home Safety.

This application facilitates home automation by using alerts, alarms and sensors at the home to facilitate the home safety. Incorporated into this service are kitchen equipment (stove and oven) control, flood, smoke and fire sensors, front door, and other equipment or situations that may pose physical threat. The electric cooking guard keeps measurements of the time, temperature, and electric current going to the stove and oven. This gives the consumer a predefined time span to use the stove (i.e., 45minutes), after which, an alert is shown on the Carebox screen and voice notifies the elderly about the cooking activity, giving them the chance to react. If the cooking activities have not stopped after another predefined time period, the system automatically sends an alarm to the informal caregiver.

3.1.3. Nocturnal Movement Detectors.

The bed occupancy sensor generates an alarm if it detects that a user has been out of bed for more than a normal period of time, subject to their individual habits. For example, the sensor can register an alert if EP starts leaving the bed several times during the night. This could signify that they are using the toilet more often — which could require a change in medication, or if they are experiencing nighttime wandering — which could signify a change in cognition, or if a person has not returned to bed—which could indicate they have fallen down while out of bed.

3.1.4. Alerts.

An alert is when the caregiver will be notified of the information but a response is not urgent. This information requires some follow-up to be carried out within a preset period of time. This includes: the refrigerator has been left open, front door has been left open, water was left running, the stove has been left on, EP is out of bed for several hours during the night, and so forth. By setting individual parameters through the scheduler, the system is set up to interpret the information transmitted from the sensors and distinguish between a normal activity pattern and unusual activity, which may indicate a change in EP's condition or needs. This enables caregivers to investigate the reason for the change and provide appropriate assistance and amend their support plan accordingly.

3.1.5. Alarms.

Alarms are sent to caregivers in case of events they wish to know of right away, such as if EP has left the house in the middle of the night. The alarm service can be activated automatically and on demand as the alarm sensors are connected to the central unit (from the Carebox computer in the home to the ISISEMD web portal) and a message informs the user about the nature of the alarm.

Alternative alarms and message flows with escalation can be foreseen in special cases (e.g., the relative is traveling abroad or is unavailable on their mobile phone) so that critical issues can be addressed properly. The alarm service itself is not only a simple event, notification or message, it can be an overall history of such messages that provides valuable information to the caregivers.

Alarms that require immediate action include:

i. door alarms — the house can be equipped with door alarms which can send an alert when the front door is opened (e.g., if EP is not safe to leave the home alone) or if there is unusual activity with the door (e.g., if EP leaves the home at odd hours, such as middle of the night);

ii. refrigerator and cooking monitoring alarm — this generates an audio alarm for EP when the refrigerator door has been left open for a specific period (e.g., longer than 7 minutes) and automatically sends an alarm to ICG if the door is not closed within a specific period from when the audio alarm is generated (e.g., refrigerator door has been opened 7 minutes and the 1 minute audio alarm to EP has not resolved the issue). The audio alarm is only generated for a specific period and stops once the alarm has been sent to the caregiver. This also enables the recording of a pattern of opening and closing of the fridge to gain perspective of the daily habits, for example, if EP is eating meals at appropriate times. The cooking monitoring alarm is operating on the same principle — after detecting that the stove is on longer than the predefined time period, the system displays an alarm message on the Carebox screen, thus giving the elderly the opportunity to react and turn off the stove or oven. The caregiver receives an alarm only when the cooking appliances are still not turned off;

iii. smoke, fire, and flood alarms — these signify imminent danger and audio alarms are generated in EPs home as well as alarms sent to caregivers.

3.2. Service Information for the Elderly

3.2.1. Reminders on Carebox.

The Carebox Touch screen computer installed in the participant's house displays text with reminders and relays attention sounds or prerecorded audio messages. The service is automatic and the user can see the reminder text and hear the attention sound and/or the voice prompt for the activity on the Carebox they are responsible for and enforce the structure of the daily routine. This aspect of the ISISEMD system is as non-interactive as possible, as people with dementia have difficulty learning to use new devices. The alert tells and shows if there is an upcoming appointment, meal, medication, or task. Reminder alerts could be used to prompt EP to take medication, prepare meals, attend an appointment or remind them of planned visitors to their home. Reminders can be automatically repeated multiple times, at short intervals. The Carebox is also automatically showing the next two events that elderly need to perform under a list of next events, but never more than 2 events at a time to avoid invoking anxiety or confusion. Furthermore, the Carebox always displays the date and time to help orient EP.

Caregivers — or possibly the elderly person, if they are able — could make a change to this schedule or enter new reminders and events (i.e., Happy Birthday), which can be accessed via the portal at any time. There is also an option for

ICG to request a confirmation to a specific reminder/activity, such as taking medications. In this case another soft button appears on the Carebox screen and if not pressed, the system automatically sends information to ICG (see Figure 1).

3.2.2. Memory Lane with Personal Pictures on Carebox.

This is a picture slide show that is shown on the upper right corner of the Carebox. The ICGs upload pictures and there is the possibility to write a short title to be displayed with each picture and the speed of the picture show can be adjusted. EP does not need to interact with this service but it is hoped that it will stimulate memories, conversations and reinforce their sense of self.

3.2.3. Brain Games on Carebox.

This service provides the EP the possibility to play Brain games on the Carebox, such as word finds, appropriate puzzles, etc. The type of game can be selected by formal or informal caregiver via the web portal.

3.2.4. Video-Call Service.

This service is mainly initiated by a caregiver — when a video call is displayed as incoming on the touch screen, EP can hear a traditional telephone ringing sound and can accept the call simply by pressing one “soft button” on the screen. If desired and able, EP can also use this service to make calls.

3.2.5. Outdoor Safety with the Lommy GPS Device.

The required technologies for this service are a GPS positioning system and GPRS communication. The GPS is useful if the client has a tendency to get confused or disoriented when they are outside the home. When EP leaves the home, they take the Lommy device with them. Through this device, they are able to contact their caregiver and can be located should the need arise. The GPS is activated when the elderly person leaves the home, and the caregiver can see their positioning on a map by logging into the ISISEMD portal. By pressing the red button (the only external feature on the Lommy), the Lommy sends a sms with the current position or directly calls the ICG (depending on the individualized settings); alternatively, ICGs can call back the Lommy as a regular telephone number and EP only needs to press the red button to activate the communication.

Alarms — an alarm is generated when EP presses the red contact button; has left the “safe” geographical area; EP has fallen down; and to signify low battery level. The device is about the size of a deck of cards and is fitted to an item the person would normally take with them when they go out, such as in the jacket pocket or purse. Additionally, we have found that placing a large picture of the device near the main door helps to remind EPs to take the device with them.

4.Methods of the Assessment

4.1. Primary Research Outcome.

The project is classified under the PSP Theme 1 (ICT for user-friendly administration, public services, and inclusion) and states a strategic objective of using ICT for aging well with cognitive problems by combining assistive and independent living technologies. Primary research outcomes consist of measuring the impact on QOL and caregiving stress in end-user groups. With respect to independent living, the aim was to demonstrate that clients can independently live longer and safer in their own home environment through the Assistive Technologies of ISISEMD. Furthermore, as ISISEMD develops assistive technologies and services, user satisfaction and acceptance were examined to assess how the end-users perceive the set of technologies as well as the services. More information for the evaluation framework for impact assessment of the services is provided in [21].

We defined the following research hypotheses:

(H_1) if the personalised services offered by the ISISEMD platform are based on each client’s specific needs, then the feeling of safety, ability for independent living in their home environment, hobbies, and lifestyle will have a positive impact on QOL;

(H_2) if the services supporting the informal carers will reduce care-related stress then a positive impact on their QOL, in particular increased feeling of safety, and reduced rates of stress levels, will occur;

(H_3) if the regional care providers will be able to offer social services to these groups of clients which are currently not included in the traditional care model, then there will be an increase in the access to and quality of social care.

Target variables and expected results:

(a) increased QOL and feelings of safety, reduced care-related stress, and maintained cognitive ability are assessed by standardised questionnaires;

(b) user acceptance and satisfaction are assessed by specifically designed ISISEMD questionnaires.

4.2. Validation of the Services.

In the four pilot sites, the validation of the services was carried out in two stages — small-scale and large-scale validation. The services were first tested in a smaller scale, with a few end-users at each site for a period for 4 months, in order to identify if any technical problems existed before large-scale testing with all users during the rest of the testing period. This was also in ethical consideration as installing technology that may require adjustments could become a source of stress in the home of persons with CI. Additionally, to have multiple persons or multiple visits from project staff could also affect QOL, either positively or negatively. After that, the pilot operation and the controlled study continued in full scale, involving the rest of the test participants. The cities involved in ISISEMD study were Frederikshavn from Denmark (denoted as FRED), Lappeenranta from Finland (denoted as LAP), Trikala from Greece (denoted as TR), and Belfast from UK (denoted as BLF). Initially, the overall period of real-life evaluation was planned for 12 months but it was later extended to 15 months.

4.3. Inclusion Criteria.

The eligible population of elderly is: *elderly over 60 years of age diagnosed with stage two (Age Associated Memory Impairment) to four (Mild Dementia), according to the GDS, with corresponding to the Mini Mental State Exam (MMSE) scores of 19–26 and living in their own homes.*

To work with a representative sample of the primary end-users, the recruitment of ISISEMD trial participants for the pilot services follows strongly defined inclusion and exclusion criteria. The World Health Organization (2007) International Classification of Diseases (ICD-10) was to be used to classify dementia type and used in conjunction with the Mini Mental State Examination (MMSE) [22] to determine cognitive status. The main inclusion criterion for primary users is the stage of disease (level of cognitive decline). The Global Deterioration Scale (GDS) was to be used as a classification standard. The main inclusion/exclusion criteria have been consulted with Bodil Gramkow, chief physician at Department of Psychological and Gerontology in Brønderslev, Denmark and Kasper Jørgensen from National Knowledge Center for Dementia in Denmark.

For assessing EP status, another mode was to administer the Montreal Cognitive Assessment (MoCA) [23] as an academic comparison tool for cognitive functioning measurements (sensitivity 90%) because MoCA is designed to screen for MCI and considers attention, concentration, executive functions, memory, language, visuo-constructional skills, conceptual thinking, calculations, and orientation in around 10 minutes. In this case, the MoCA score for inclusion would be less than or equal to 26 following the same cognitive functioning parameters as for the MMSE.

The eligible population of informal caregivers was adults over 18 years and they were recruited based on their relationship with an elderly test participant.

Tables 1 and 2 summarise the inclusion and exclusion criteria for EPs and ICGs. As our research progressed, we needed to make modifications to the inclusion and exclusion criteria. They are explained in Section 5.

Table 1. Inclusion and exclusion criteria for EPs

Factor	Age	Medical diagnosis	Living arrangement	Caregiver
Inclusion	Over 60 years old	GDS Stage 2-4; MMSE and MoCA score of 19-26	Lives in home dwelling	Have ICG
Exclusion		GDS beyond stage 4; dementia secondary to head trauma, bedbound, malignant illness, psychological conditions similar to dementia; misuse of alcohol or medications; frontal temporal dementia; more than 3 acute hospitalization sin the past 12 months	Planning long-term care admission in 6 months or less	Do not have someone in the role as ICG

Table 2. Inclusion and exclusion criteria for ICGs

Factor	Age	Mecial diagnosis	Living arrangement	Caregiving
Inclusion	18 years or older		Live with EP; Do not live with EP but provides regular, direct assistance; No plans to move for the duration of the trial	Already involved in caregiver role for 6 months or longer
Exclusion		Active treatment for cancer; has dementia	Planned placement of EP in long-term care in 6 months or less	

4.4. Statistical Considerations and Forming of Test and Control Groups.

ISISEMD-controlled study on intelligent systems for dementia home care is a randomized control trial. Allocation concealment was implemented in order to assign the patients in the intervention and in the control arm of the study. The *intervention/test group* was provided the ISISEMD telecare platform while the *control group* received standard care services through their ICGs and municipality. Because of the nature of the intervention, masking of the intervention could not be performed (since the telecare platform was visible and some of its functions were interactive). The trial followed a single-blinded pattern in which the principal investigators conducting the assessments were not the researchers analyzing the data from the evaluations.

The overall hypothesis for ISISEMD project is that ICT services will improve QOL for those with cognitive impairments or mild dementia. The end-user partners are not aware of previous research to document such a hypothesis with a controlled study. Previous studies in this area have only found that there is a relation (Logsdon [24]). So, in reference with Logsdon [24], our assumptions are: *"…it could be expected an average score of QOL-AD at approx. 39.5 points (spreading 5.3) among a test group. In ISISEMD project, we will try the ICT service for N = 97."*

We were aiming to be able to measure increased QOL with 6%, spreading 5.3 and P value of 5% is calculated that $N = 37$ persons to be used in the test group, in order to prove the hypothesis with significance. Because of this reason, the number of test elderly persons was defined to be $N = 40$ in the test group, meaning 10 persons in the test group and additionally 10 persons in the control group for each region. All in all, overall for the controlled study $N = 80$. Additionally, in order to have statically valid test results, the test and control groups of the elderly were planned to be randomly selected. This was to be done by a small lottery.

Wilcoxon Test.

Please note that instead of regressions analysis, which is not a suitable test in our case due to the small number of test subjects, a Wilcoxon test was conducted. For small number of observations, we assume that distributions in scores and data are non-normal. The Wilcoxon Signed-Rank test detects differences in the distributions of two related variables. Small significance values (<.05) indicate that the two variables differ in distribution.

4.5. Ethical Aspects.

When testing ICT services with human participants, it is necessary to obtain approval from national and regional Ethical Committees before the trials begin. This ensures that the ethical rights of the citizens are respected and that the testing is carried out according to the national and international regulations. For the ISISEMD controlled study, all required approvals from data protection agencies and ethical regional committees were obtained. Consent forms were signed by all persons in the study and details of the main person to contact from the social care provider organization were provided to all study participants. A short brochure with more information about the ISISEMD services was given, together with short description of the project and statement that all data is treated anonymously. As the ISISEMD pilot involved human participants, a number of ethical and legal considerations were considered and followed:

i. *the right to be informed*: any participant in ISISEMD has the right to know the purpose of the activity they are involved in, the expected duration, procedures, use of information collected, their rights as a part of the study and any risks, discomfort, or adverse effects. This information was conveyed during the recruitment process and then reiterated when the *informed consent* form was distributed and signed by the participant;
ii. *permission to record*: before recording the voice or image of any individual, permission will be obtained through the consent form;
iii. *anonymity*: participants have a right to anonymity, meaning that their information was kept confidential and names were never associated with data or other personally identifiable information;
iv. *the right to withdraw*: participants should feel free to withdraw from any activity without penalty;
v. *valid and reliable data*: in every activity, we ensured that the data we collected was free from bias, accurate, valid, and reliable;

vi. *data retention and documentation*: collected original data will be retained only for as long as it is relevant for the project.

In Greece, the Institutional Review Board (IRB) of the ISISEMD study was the Independent Authority of Personal Data Protection. In Denmark, the ISISEMD project was approved by the Data Protection Authority while the Local Scientific Ethics Committee for North Jutland Region was notified about the study with a full description of it and followed the rules set by the National Scientific Committee (and the Helsinki declaration). In Belfast, approval was sought from the Research Governance Department of the Belfast Health and Social Care Trust and the Northern Ireland Regional Ethics Committee and Lappeenranta obtained authorization from the local and national Social and Health Services and Ethics Committee. The IRB and the Data and Safety Monitoring Board were the same body.

4.6. Data Collection Tools

4.6.1. User Acceptance and Satisfaction.

In [25], Dillon and Morris present user acceptance as “the demonstratable willingness within a user group to employ information technology for the tasks it is designed to support.” Davis [26] developed the Technology Acceptance Model (TAM), which proposes that the acceptance of AT will be correlated with perceived value and ease of use. User acceptance and satisfaction, discussed in this paper from the perspective of the ICG, is assessed from both the technical and nontechnical perspectives. By technical perspective, we mean that perspective in which the ICG finds the technology easy to use, accurate, and functional for their caregiving responsibilities.

In ISISEMD, user satisfaction is evaluated by the end user’s assessment of the multiple aspects of the service. This means that user satisfaction is considered a multidimensional concept, incorporating the perceptions of end users based on their personal, subjective attitudes and values. To collect data, we used a triangulation of methods consisting of questionnaires, interviews, and structured observations with the users to determine their acceptance and satisfaction with the ISISEMD services. ISISEMD questionnaires for user acceptance and satisfaction have been inspired by The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0) [27, 28] and ETUQ — Everyday Technology Use Questionnaire [29] — and were administered to both EP and ICG groups.

4.6.2. Quality of Life for Informal Caregivers.

There are few instruments measuring QOL for caregivers of chronically ill patients. A more recent and advanced assessing tool for measuring QOL of informal caregivers, specifically designed for carers of patients with cognitive problems, is the Scale of Quality of Life of Caregivers (SQLC) [30]. This tool was used in the controlled study, covering 3 domains: professional activities, social and leisure activities and responsibilities of caregivers to help patients in everyday living. SQLC scoring provides 4 categories of Caregivers’ adaptation: full psychosocial adaptation (141–145), mild disturbance (100–140), moderate disturbance (86–99) and severe disturbance (<85).

4.6.3. Stress of Caregiving.

Assessing caregiving stress involves an evaluation of how the caregiver experiences the caregiving task to be, involving objective parameters (e.g., number of tasks, time per task) and caregiving capacity (e.g., amount of available time, proximity to care receiving residence), among others. To measure caregiver stress as well as effects from interventions aimed at reducing it, the Zarit Burden Interview (ZBI) short version [31] was used in ISISEMD. Questions are on caregiver’s health, psychological wellbeing, finances, social life, relationship between carer and patient, and a lower score indicates lower perceived stress. More information about the overall evaluation framework for ISISEMD services with description of the mentioned data collection tools is presented in [21].

4.7. Data Collection Methods.

Collection of the study data was carried out at three stages — at baseline, at intermediate, and at final stages. The pilot started in May, 2010, and final data collection took place in June, 2011. It must be noted, though, that the pilot services have been used with different duration in the regions—in Lappeenranta and Frederikshavn since May, 2010, in Belfast since July, 2010, and in Trikala since September, 2010. The intermediate evaluations that we describe in this paper took place in February, 2011, while the baseline evaluation for the clients was carried out before the services were installed in their homes. The participants that carried out the intermediate evaluations in February, 2011 were those who were using the services long enough in order to get used to the technology and to observe a difference in their every day. Their number is provided in the sections for the primary and secondary outcomes of this study.

The intervention and the control groups of EPs and ICG were administered the same ratings scales and questionnaires except the user satisfaction and acceptance. The rating scales for SQLC and ZBI for ICG were administered at baseline, intermediate and final stage for the intervention group, while for the control group — the same rating scales but only at baseline and final stage. In this paper we present the baseline and intermediate results from these for the test group. For EPs, the rating instruments used were MMSE, ADL, IADL, and QOL-AD but the results from them are not the subject of this paper.

5. Results

5.1. Recruitment of Participants.

The test participants from the four countries were recruited using different channels. The majority of referrals were contacted via memory clinics or by the home-care personnel. But we also used TV and radio channels to announce the pilot study and attract interested participants.

The control EP group was as characteristically similar to EP group as possible. Participants were also recruited with the aid of general and nurse practitioners, memory and dementia clinics, and regional organizations working with dementia populations. They were going to be involved as the test participants from the beginning months of the test period and relevant tests were applied to them too. Control group was also administered all tests for the test group except test user acceptance and user satisfaction because they were not given any technological intervention.

As the regional end-user organizations began to identify potential clients, we have had to make amendments in our inclusion criteria and parameters. As none of the care provider organizations were familiar with the GDS scale, it was determined that we would classify the level of cognition based on MMSE scores only. Likewise, not all participants had a medical diagnosis of dementia and accompanying stage, many were referred by professionals who noted cognitive impairment and probable dementia or by their relatives. Since we were not using the GDS as our measurement, we no longer were restricted to the 19–26 score range in the cognition scales. We observed that the elderly participants from the target group, in most of its majority, were not receiving any dementia care because this type of care is usually offered to clients with severe dementia. They were mainly known to the FCGs from receiving traditional home help. We also noticed that overall, there is little awareness in the society about the early signs of dementia and the care stress of the informal caregivers and that the early stages of illness are not diagnosed. A fact that is also confirmed by a recent study in UK from the Alzheimer's Association.

Additionally, we had initially specified that we would exclude participants who have dementia secondary to head trauma as well as those who are bedbound (confined to a bed or chair for 20 hours a day for 4 out of 7 days). In Region Frederikshavn, there was one EP who has cognitive impairment secondary to head trauma and is confined to a wheelchair due to a work (fishing industry) accident. The case of this participant was discussed with the other care provider organizations and it was determined that this subject and the informal caregiver would remain in the trial because they are only utilizing the Lommy (GPS) service and both EP and ICG give valuable feedback regarding the ISISEMD equipment and services. It is also noted that the main constructive outcomes in this case will be in the evaluation of services and QOL rather than in the correlation between cognitive functioning. There was also one participant that was not willing to take the tests for the cognitive impairments, neither at the baseline, nor at the final evaluations because he felt offended by the questions. Furthermore, there were some EP subjects with MMSE scores outside range 19–26. From the intervention group, there were $N = 3$ with MMSE < 19, $N = 2$ with MMSE > 26. From the controls, $N = 5$ with MMSE < 19, $N = 7$ with MMSE > 26.

5.2. Number of Participants.

The goal of the controlled study was to include 80 elderly patients with MCI or mild dementia (MD) across four regions — 20 per trial site (10 intervention and 10 control participants) with respective number of informal caregivers. However, it must be noted that it was a very challenging task to recruit test participants for the study due to several reasons. The partners from the regional organizations invested a lot of effort in these activities and normally two to three times more referrals have been approached and interviewed in order to fit the inclusion criteria. Also, due to some procedural delays in some of the regions for obtaining ethical approvals and appointing staff to work on the project, the pilot operations did not all start at the same time in all of the four pilot sites. There were also issues with some participants experiencing a rapid change in cognitive or health status that excluded them from the trial by the time they began, which is not uncommon in this field of research. Therefore, in the selection procedure we could not follow the randomization of the test and control participants. Priority was given to include the target number of participants in the intervention group, therefore the controls were recruited after the recruitment of the intervention group. In Frederikshavn pilot site it was not possible to recruit any participants to be in the control group.

Table 3 presents the number of subjects from the intervention and control group and the number of drop outs from the intervention group. The most common reasons for drop outs were that the overall health status degraded significantly and elderly were admitted to institutional care, or participant had a stroke and was not able to continue the pilot or the services could not be installed in their homes due to problems to provide internet connection. Another reason was that after signing the consent agreement forms the baseline tests were administered but there was a sudden change in family plans and the drop-out took place before the equipment was installed. Other reason for dropouts included family issues. Only one dyad dropped out from the intervention group due to the number of false alarms during the initial months of the small-scale pilot and because EP considered their own health good enough to manage without trying the services.

Table 3. Number of participants in ISISEMD-controlled study

Region	EP intervention (N=31)	EP (intervention) dropouts since start (N=14)	EP controls (N=26)	Total EP participants until end of pilot (N=71)
FRED (Denmark)	6	4	0	10
BLF (UK)	7	5	10	22
TR (Greece)	10	3	5	18
LAPP (Finland)	8	2	11	21
Region	ICG intervention (N=31)	ICG (intervention) dropouts since start (N=14)	ICG controls (N=26)	Total ICG participants until end of pilot (N=71)
FRED (Denmark)	6	4	0	10
BLF (UK)	7	5	10	22
TR (Greece)	10	3	5	18
LAPP (Finland)	8	2	11	21

5.3. Participant Characteristics

5.3.1. Characteristics of the ICG Sample.

In total ICGs $N = 71$ participated overall in the control study, with $N = 45$ in the intervention group and $N = 26$ controls. From the intervention group, there were $N = 14$ dropouts due to a drop out of the elderly. Overall, the female ICGs were 70.89%, 64.86% intervention, and 76.92% controls. 67.56% of the intervention group had a previous experience with computer, while 83.78% of the intervention group had a previous experience with a mobile. 82.28% from all of them lived in the same area as their elderly with 83.78% from the intervention and 80.77% from the control. The percentage of the children was highest — 57.80% overall (54.05% intervention and 61.54% from the control). The second high was the percentage of the spouses — 41.22% overall (32.43% intervention and 50% from the control), the rest were other type such as neighbors or some volunteers who were helping the elderly. Mean age, in years in the intervention group was 54.89 years ($N = 27$, SD 12,939) while the control group had 62.23 mean age ($N = 26$, SD 13,131).

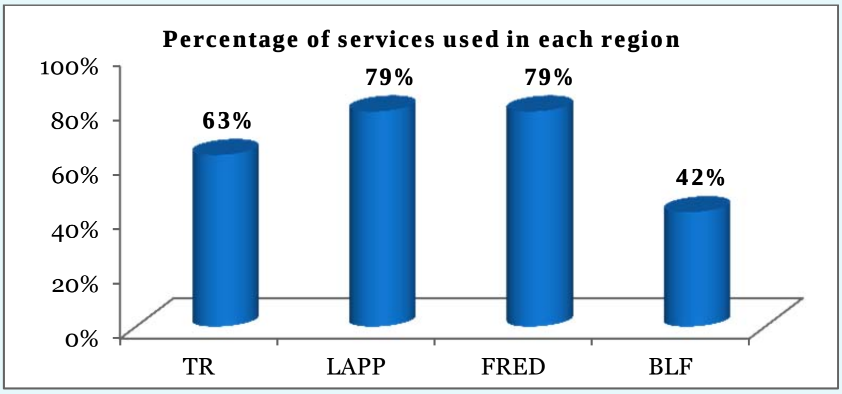
5.3.2. Characteristics of the EP Sample.

In total EPs $N = 71$ participated overall in the control study, with $N = 45$ in the intervention group and $N = 26$ controls. From the intervention group, there were $N = 14$ dropouts due to reasons mentioned above. Overall, the female EPs were 64.55%, 67.6%, intervention and 61.5% controls. Only 8.1% of the intervention group had a previous experience with computer, while 51.35% of the intervention group had a previous experience with a mobile. 47.6% from all of them lived alone, with 56.7% from the intervention and 38.5% from the control. Mean age for EPs, in years, in the intervention group was 77.38 ($N = 37$, SD 8.060) while the control group had 80.00 mean age ($N = 26$, SD 8.23). The cognitive functioning for EPs, depicted with MMSE scores, was: for intervention group mean = 22.12 ($N = 34$, SD 3.79) and for the control group mean = 22.29 ($N = 24$, SD 5.44). After analyzing the data from the regions, we found that that in the intervention group ($N = 37$), the most EPs living alone were in LAP (90%, $N = 10$) and in FRED (70%, $N = 10$) and the least were in Belfast (14%, $N = 7$), in TR they were 40% ($N = 10$). Overall in the intervention group ($N = 37$), the male EPs were less than the female EPs with highest percentage in FRED (50%, $N = 10$) and the smallest percentage in LAP (10%, $N = 10$), while in BLF it was 43% ($N = 7$) and in TR it was 30% ($N = 10$).

5.4. Use of the Services.

From all services that were offered via ISISEMD service platform and available during the test period of the controlled study, not all of the services were tested in each home because each elderly received a subset of all services deepening on his and relative's individual care needs. Figure 2 shows the average use of the services in the four sites. To identify which service each elderly needed at baseline, an evaluation of basic activities of daily living (ADL) and the instrumental activities of daily living (IADL) was carried out, together with an interview with the informal caregivers about their needs and if the elderly had any incidents recently (such as being lost, any falls, cooker turned on and forgotten).

Figure 2: Average use of the services in the four cities (*N* = 31).



5.5. Observations from the Baseline Evaluations.

We would like to summarize the following observations from the baseline evaluations:

i. highest percentage of services utilized was in Lappeenranta (Finland) and Frederikshavn (Denmark);
ii. Trikala (Greece) had the most end users living alone (100%);
iii. most of the EPs and ICGs were women, which follows global trends for these groups;
iv. according to MMSE scores, in Belfast (UK), EPs have moderate impairment, while the rest is in mild to moderate stage;
v. in Lappeenranta (Finland) and Frederikshavn (Denmark), ICGs report a "moderate effect" on QOL before the intervention, while in Trikala, Greece and Belfast, North Ireland, the effect on ICG QOL was reported as "severe";
vi. the highest reported caregiving-related stress for ICG is in Frederikshavn (Denmark).

In the following sections we present more detailed information about the results from the intermediate evaluations.

5.6. Primary Outcomes: Quality of Life and Care-Related Stress for Informal Caregivers.

The participants that carried out the intermediate evaluations in February, 2011 were only from the intervention group and those who were using the services long enough in order to get used to the technology and to observe a difference in their every day. Their number is provided in each of the tables for the primary and secondary outcomes of this study. Table 4 provides data about the nature of the caregiving relationship to the older adult, QOL in the ICGs via SQLC and reported level of care-related stress through the ZBI scores from baseline and intermediate assessments. SQLC and ZBI rating scales were administered among ICGs at the intermediate evaluation in all three pilot sites except Frederikshavn.

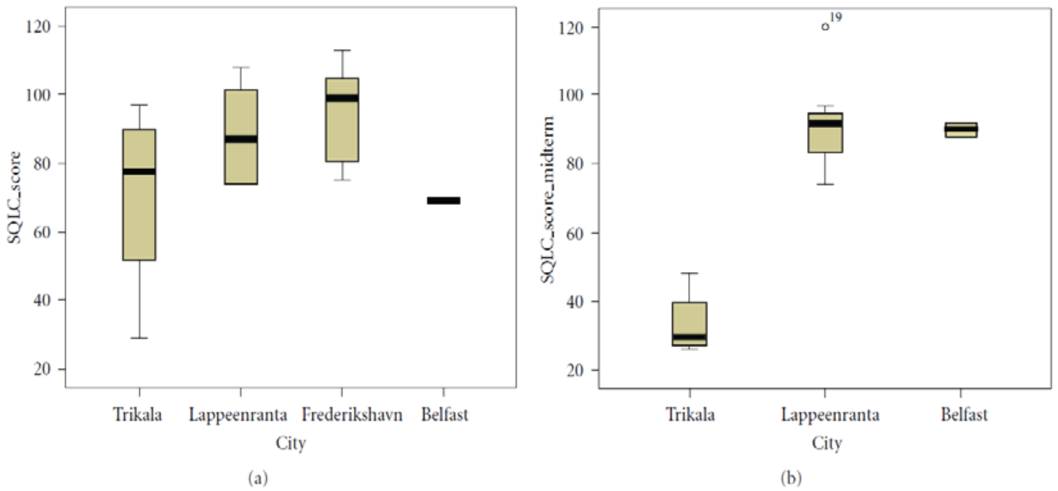
Table 4 is showing that, on average, the adaptation of the caregivers is within the same range — but that range is also the lowest, showing severe disturbance to ICGs QOL. However, we can observe that the median (middle score of all assessments) SQLC score increased, from severe disturbance to one of moderate disturbance. As well, the mode (most commonly reported assessment result) increased from severe to moderate as well as the maximum score increased for the follow up. We can also observe that the average (mean) level of caregiver stress dramatically decreased from 31.82 to 14.83, meaning from on the moderate side to little to no caregiving-related stress. The median (middle score) also decreased as well as the most reported score (mode) and the maximum level of stress reported dramatically decreased (from 105 to only 24 being the highest reported level of stress). SQLC score at baseline (*N* = 27) had mean value 81.96 (SD 21.283), with minimum = 29 and maximum = 113. SQLC score at intermediate (*N* = 13) had mean value 73.46 (SD 30.341), with minimum = 26 and maximum = 120. This shows, again, that the reported QOL of ICG has decreased.

Table 4. ICG percentages, SQLC and ZBI baseline and intermediate scores

	ICG: Child	ICG: Spouse	ICG: Other	SQLC baseline	SQLC intermediate	ZBI baseline	ZBI intermediate
N observations	35	35	35	27	13	7	12
Missing	0	0	0	8	22	7	23
Mean/percentage	62,9%	20,0%	17,1%	81,96	73,46	16,06	14,83
Median	-	-	-	85,00	88,00	21,00	15,00
Mode	-	-	-	74	92	16	14

Boxplots of SQLC scores according to city are presented in Figure 3. Frederikshavn had the highest baseline SQLC score, while Trikala and Belfast had the lowest baseline SQLC score. In intermediate scores, Trikala seems to be by far the lowest scoring city in SQLC, while Lappeenranta and Belfast seem to be close in scoring; there are no available intermediate SQLC scores for Frederikshavn. In terms of difference between baseline and intermediate SQLC scoring, Trikala seems to be the city with the largest drop in scores, while Lappeenranta's scoring seems to range in the same levels; Belfast seems to have small increase in SQLC scores, however there are only few data available for intermediate scoring in this city.

Figure 3: Boxplots of SQLC scores (baseline *N* = 27, intermediate *N* = 13) according to city.



Boxplots of ZBI scores according to city are presented in Figure 4. Trikala seems to have the highest baseline ZBI scores, while Lappeenranta and Frederikshavn seem to have the lowest baseline ZBI scores. At intermediate scores, Trikala seems to be the lowest scoring city in ZBI, while Lappeenranta and Belfast seem to be relatively close in scoring; there are no available intermediate ZBI scores for Frederikshavn. In terms of difference between baseline and intermediate ZBI scoring, Lappeenranta seems to be the city with the largest increase in scores, while Trikala's scoring seems to range in the lowest levels; Belfast seems to have a decrease in ZBI scores. ZBI score at baseline (*N* = 28) hadmean value 16.06 (SD 8.11), with minimum = 0 and maximum = 33. ZBI score at intermediate (*N* = 12) had mean value 14.83 (SD 7.095), with minimum = 0 and maximum = 24. This shows, again, that the reported care stress of ICG has decreased.

Figure 4. Boxplots of ZBI scores (baseline *N* = 28, intermediate *N* = 12) according to city

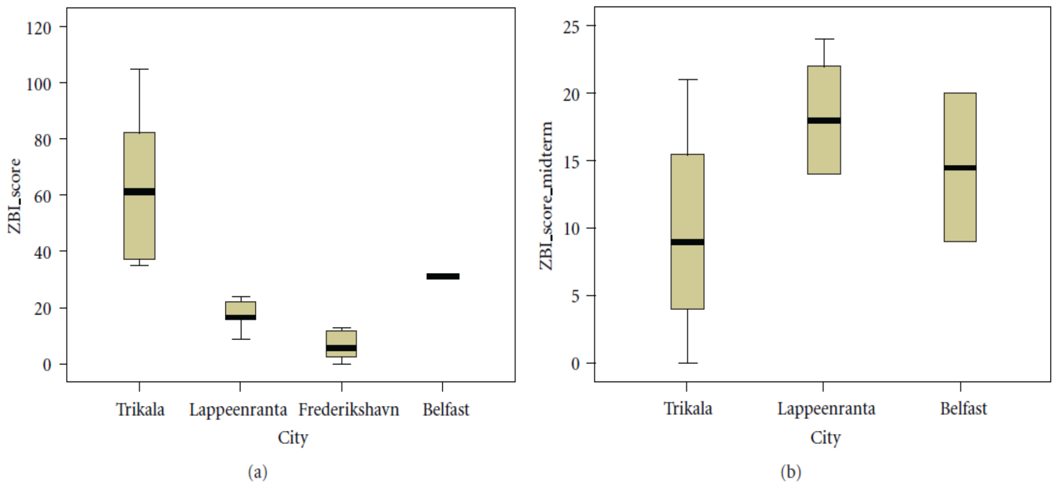


Table 5 examines the normality in the distribution of values for the SQLC and ZBI scales (baseline, intermediate). When *P* value <0.05 the values do not follow a normal distribution (this determines the choice of the statistical analysis that we are using: when variables are not normally distributed we use nonparametric methods). In our case, if we use the first statistical criterion (Kolmogorov-Smirnov), the distribution is non-normal and due to our small sample (small number of observations), we assume that distributions in scores and data are non-normal. For the above reason we run a Wilcoxon test, as it was not possible to conduct a regression analysis (the criteria for using regression analysis are not met).

Table 5. Tests of normality

	Kolomogorov-Smirnov (a)			Shapiro-Wilk		
	Statistic	Df	*p*-value	Statistic	Df	*p*-value
SQLC score	0,195	8	0,200	0,869	8	0,147
SQLC score intermediate	0,209	8	0,200	0,838	8	0,072
ZBI score	0,275	8	0,077	0,831	8	0,061
ZBI score intermediate	0,174	8	0,200	0,951	8	0,721

Table 6 provides results from the Wilcoxon test for SQLC, ZBI. The Wilcoxon test examines whether the SQLC scores show significant differences at intermediate evaluation: The significance, "Sig" (*P* value), which is larger than 0.05 (*P* = 0.153) shows that the differences are not significant (even though at baseline the Mean was 81.96 and at intermediate it was 73.46). Similarly, Wilcoxon tests for ZBI and SQLC scores found no significant differences between baseline and intermediate (with *P* = 0.123 and *P* = 0.536, resp.).

Table 6. Wilcoxon test for baseline and intermediate results of the Scale of Quality of Life of Caregivers and Zarit Burden Interview

	SQLC score intermediate – SQLC score	ZBI score intermediate – ZBI score
Z	-1,428	-1,542
Asymp. Sig. (2-tailed)	,153	,123

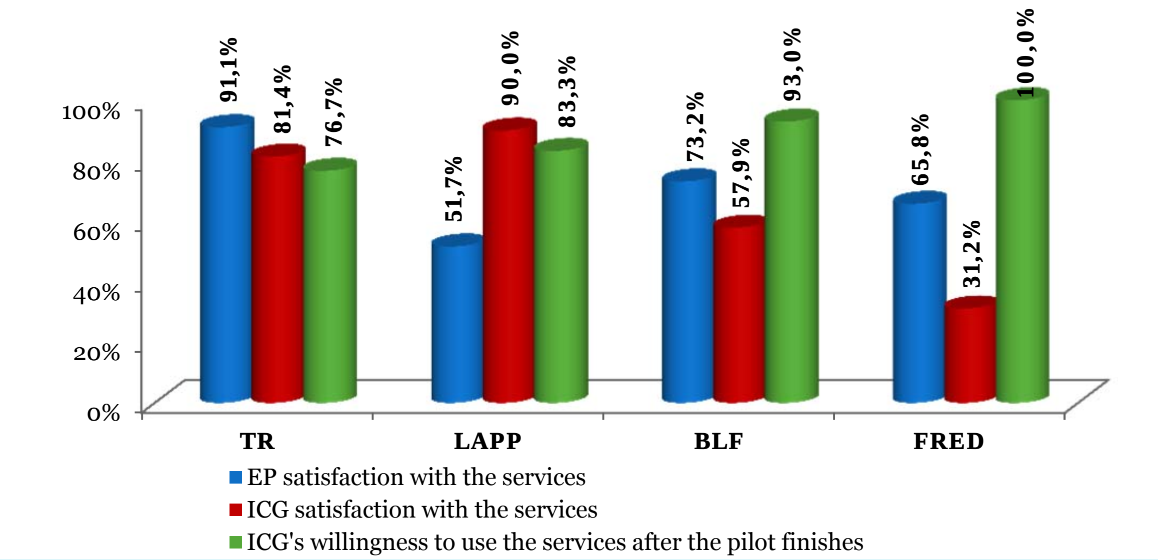
For these two (SQLC and ZBI), showing *no significant difference*, we would like to state that this has, statistically, shown that ISISEMD services can at least maintain QOL in family caregivers. It appears that the lack of sufficient data at present does not permit us to conclude that there is a significant difference (in either direction) between baseline and intermediate.

5.7. Primary Outcomes — User Satisfaction.

Intermediate evaluation for user satisfaction with the services was carried out with 17 EPs and 17 ICGs from the intervention group from the four regions and gave positive results overall—on average 70.45% for EP and 65.12% for ICGs and 88.25% of both groups indicate that they would like to continue to use the home support services after the end of the project. Access to care for elderly was increased with 100% for all test elderly persons because they did not receive this type of care before. Another positive effect of using the services for the informal caregivers is that they give them possibility to save time and money on travel and phone calls to the elderly, gives them more freedom for their personal life and free-time interests, reassurance and peace of mind.

Figure 5 presents the results from user satisfaction and willingness to use the services after the pilot finishes, in percentage for the four regions separately. For satisfaction 100% = full satisfaction, 0% = not satisfied; for willingness to use 100%= I would definitely use a system like this, 0%= I would not use a system like this. They are based on the flowing number of subjects: TR-EP *N* = 4; ICG *N* = 4; LAP-EP *N* = 7; ICG *N* = 7; BLF-EP *N* = 2; ICG *N* = 2; FRED-EP *N* = 4; ICG *N* = 4.

Figure 5. User satisfaction results from the intermediate evaluation – overall for EP and ICG participants (intervention group)



It must be noted that, from a technical perspective we faced some unexpected technical issues with stability and availability of the services in real-life conditions during the first couple of months in Frederikshavn and Belfast which influence the results from this intermediate evaluation and thus shows lower percentage of satisfaction. For the final evaluations, we will be investigating correlations between particular age group of ICGs and their changes (using regression analysis) and correlations between living status of ICGs to EPs.

5.8. Secondary Outcomes — The Services Are Appreciated Differently in the Four Regions.

During the intermediate stages of the project, when we were designing the needed services, the care provider organizations and end-users from all four pilot sites participated in collecting user requirements. So the list of services to be technically implemented in ISISEMD system was a collective list, addressing the overall needs. However, due to country specifics, as we found out already from the intermediate qualitative evaluations, some services were more popular (the end-users liked them most and/or considered them most important for the care provision and quality of life) in some of the regions than in the others. Here we presented the specifics we observed:

i. EPs from Frederikshavn, Belfast, and Trikala are more interested in having the services for outdoor positioning from *Lommy*, compared to users in Lappeenranta;
ii. home safety services — *fire alarm* and *cooking monitor* are considered most valuable for caregiving and personal safety in Frederikshavn, while in Lappeenranta, these are the *Intelligent front door* and *Person out of home for too long service*;
iii. elderly users from Frederikshavn, Belfast, and Lappeenranta appreciate *Memory Lane* service because it gives them something very personal and facilitates conversations with family and other visitors;
iv. *date and time services* are appreciated by EP in all regions as they reinforce the structure of the day and gives the elder the feeling that they manage better in daily routines, giving them more independence;
v. elderly and relatives find the *Reminders service* helpful with reminder prompts, and even more the prompts by an external person reduced the stress and aggressiveness in the relationship EP-closest family member since EP was more prone to listen to the reminders coming from the system than from the family member.

5.9. Secondary Outcomes — Positive Influence for the Informal Caregivers and the Elderly Persons.

Despite of the quantitative results from the intermediate evaluations, positive socioeconomic effects were experienced by both EP and ICG. There are indications for the following positive influence for the informal caregivers:

i. reduced number of phone calls by ICG to check on EPs condition;
ii. reduced number of visits done by ICG to check on EP's condition;
iii. reduced number of times ICG discusses every day issues related to the illness with EP;
iv. increased possibility for ICG to do free time or personal activities out of house;
v. reduced time spent to drive/travel to visit the EP.

There are indications for the following positive influence for the elderly:

i. EP goes out of house on him/herself more often (reduce social isolation);
ii. reduced number of times per day EP calling on the phone to ICG;
iii. reduced number of times per day EP asked ICG for future events.
iv. reduced number of times per day EP asked ICG for day/time orientation.

Additionally, in ISISEMD controlled study, we have found that the end users themselves provide much more information as to dementia care, caregiving and independent living than we had anticipated. Some end users find new uses for the technology or equipment that was not envisioned by the developers as well as presented useful feedback on the functionality of the system. Examples of this are further described in the appendix with the qualitative results from the study.

6. Discussions of the Results from the Intermediate Evaluations

The ISISEMD European project aims to improve the care and Quality of Life of elderly persons with cognitive problems or mild dementia, while evaluating the care services provided. In the context of this project, during the intermediate evaluations, 17 informal caregivers (ICGs) from 4 different geographical regions (Greece, Finland, Denmark, and UK) and their relatives with CI have been asked to evaluate the care services provided, in relation to the new assistive technologies, as well as the impact these have on their everyday life. The Scale of Quality of Life of Caregivers (SQLC) and Zarit Burden Interview (ZBI) evaluation were employed at baseline and at intermediate stages. The intermediate evaluation was carried out after an initial test period of 6 to 10 months.

During the whole process of piloting the services in real life, we observed that even when EPs and ICGs were skeptical in the beginning, after giving them time to get used to the technology, the elderly and their relatives accept the technology and can see the opportunities for positive impact. Since the targeted population have cognitive impairments or mild dementia, we found that it is most beneficial if the services are introduced as early in the disease progression as possible and it takes about 4–6 weeks for EP to get used to the system. Of course, during this period, some effort is needed from ICG to remind them to refer to it. It also helps if the Carebox touch screen is placed close to a TV (a device to which all elderly are used to) or such place in the house where the elderly spends most of the time. The deferent levels of interaction with the system, presented in Section 3, also help for the individual acceptance. The Memory Lane service was very much appreciated by the elderly and it was also a point of reference to the Carebox. Since the service platform is quite flexible, a number of settings can be made in order to adjust the services to the progression of the dementia. For example in the initial period of having the system, the Help button on the Carebox can be visible and EP can get in contact with ICG. Later, it can be "removed" from the Carebox. All in all, if EP cannot interact with the system, this is not needed but the home safety services keep ICG informed about the safety of EP.

In most of the cases, the family caregivers prefer receiving notifications and alarms by SMS instead of by email. Family caregivers are also less sensitive to the service cost compared to elderly. It seems that they are interested in having such a solution in the home in order to increase the level of independent living of their relatives. This is mainly due to the fact that relatives are in the middle age and they have a higher income in comparison with the elderly, and also due to the ICGs having spent more time and money on technology than the elderly EPs. In addition, relatives would like to have a system that offers a high degree of independence for the elderly.

The automation degree of the services is also of a key importance for the family caregivers, as we found out. Informal caregivers were also willing to have very few degree of interaction with the system. This is mainly due to the fact that they understand, on the one hand, that elderly is not able to be familiar with the new technology and on the other hand, they are willing to increase the level of independence of the elderly. Their busy everyday life also plays a role. In addition, elderly do not want a lot of user interactions with the system, since they are not familiar with the new technology and have somewhat of an aversion to learning. We have also seen that this may discourage use of the system, as the EPs may worry that they will break the technology, so they would rather not use it at all than be the cause of expensive repairs. The EPs want the system to be as automatic as possible; however, they want inexpensive technological solutions. According to the statistical analysis of the available data, no significant differences are shown in the evaluation scores provided by ICGs at the intermediate evaluation after 6–10 months from the baseline period. However, we can say that this has, statistically, shown that ISISEMD services can at least maintain QOL in family caregivers and alleviate care-related stress. A relatively high satisfaction with the services is shown by both the elderly and the informal caregivers. Moreover, the qualitative feedback from the elderly and the informal caregivers depicts positive impacts from using the ISISEMD services.

New data are expected to become available from the final evaluation in June 2011, also including the rest of the test participants. We hope for that the final evaluation, involving around 60 EPs and 60 ICGs from both intervention and control group would allow us to support our hypothesis with a statistical significance.

7. Conclusions

As one of the formal caregivers from ISISEMD consortium stated, *"it is quite a challenging task to design technology services to support persons with dementia living at home and their caregivers because it is not like designing services for physically handicapped persons."* Part of the challenges comes from the fact that each person with dementia has specific individual needs depending on how the disease progresses and on the support he or she gets from the closest family. The use of technology as support for persons with dementia living at home sets different requirements for the development of services. Different kinds of technology solutions are needed depending on individual personal factors. Furthermore, it is important that the system works with a minimal interaction and with automated operations because of limited learning abilities among the users or because they have very little experience with the new technologies.

We would like to thank our test users whom we accept as an equal partner of the consortium. They played a very important role in the process of bringing the services to a mature level and improving them in all aspects in order to meet their needs as best as possible. We can confirm that it is of high importance that the primary user and caregivers to be motivated towards usage of aiding technologies in their homes. For the acceptance of the services by the elderly, a key role plays their family caregiver and the process is much faster and easier if the caregivers have previous experience with technology.

We know that skeptical users are stoppers against introduction of new technologies. But our experience shows that the elderly and their relatives accept the technology and can see the opportunities for positive impact and added value from the use of the services in their everyday life after giving them time to get used to the technology, even when EPs and ICGs were skeptical in the beginning. It can be expected that after about one month, the elderly and the family caregiver can get used to the services. The most successful adoption of the services can happened when they are offered as early as possible in the history of the disease—in this way the technology services can be integrated in the coping and care strategies in the family and the elderly has highest chances to learn to refer to the Carebox with the reminders and to use the Lommy device.

Appendix

Qualitative Results from Service Use

During the pilot operation, the researches collected a number of good stories from the test participants, showing how the services helped the elderly (EP) or informal caregivers (ICG) in their daily life or how the users adopted the services and used them in their own way to fit individual needs and desires. Some of the examples are listed below, showing the results from the qualitative evaluations.

i. *Help Button on the Carebox.*

One of the difficulties EP faces is to use the telephone to call relatives. She is now used to using the Help button on the Carebox to make a contact with them. When she wants to get into contact with her ICG, she presses the Help button on the Carebox and makes very easy contact as the help button sends a text message to the family caregiver's mobile phone. If the ICG is at work, he is notified of this but in such a manner that it does not cause alarm. Although this service of the Help button was designed to be an easy way to contact someone if the elderly person needs immediate help, this particular user and her family have found that the easy functionality replaces her need to use the telephone, which has become too difficult for her.

ii. *Free Text Reminders on the Carebox.*

One ICG uses the free text reminders to write to their EP to perform different small tasks. "It is like sending a SMS (text message) to the elderly but it is shown in larger letters on the Carebox because elderly cannot read SMS." Another ICG uses the free text service to reinforce family humor, writing inside jokes or anecdote to EP such as, "have a glass of wine with your evening meal."

iii. *ISISEMD Services Overall.*

The formal caregivers observed that the services improve communication and relations among the elderly and family caregivers. The ICG can upload pictures on Memory Lane service to be seen by elderly, which also gives them something to discuss when they are together, "Did you see the pictures of your anniversary party on the Memory

Lane?”. Moreover, the reminders “spoken” from the system help reduce the stress in the relationship among the elderly person and the family caregiver.

iv. *ISISEMD Services Overall.*

One family carer who is the son of a female test person noticed savings of his time and travel costs. In his mother’s home, home safety services were installed (fire/smoke sensor and cooking monitor), together with the Carebox touch screen. Before installing the services, he was driving to visit his mother several times a week, but now he can see her activities via the ISISEMD web portal, and knowing that the home safety sensors will send him sms in case of smoke/fire or too long cooking activity, he feels much safer and does not need to drive there so often; the distance to her home is 7 kilometers. He does not worry all day long anymore because she knows how to contact him through the Help button on the Carebox if she needs anything. Only first after using the services, had the son realized how stressed he was in caring for his mother and the benefit that he gets from using the services is beyond his initial expectations. Furthermore, with dementia progression, he noticed from the overview of the daily events that his mother does not cook any more during the week days. For preventing of losing more weight, the sonmade everyday reminders to his mother via the Carebox for having regular meals.

v. *Outdoor Safety with Lommy.*

Another elderly who is living alone is suffering from memory problems and severe diabetes for several years. He must walk every day in order to get the blood pressure in his feet down. Before he received the ISISEMD services, there has been an incident when he left home and felt very confused during his walk and a person in the neighborhood helped him find his way home. Last winter he was not walking outside at all because he was afraid to get lost, based on this previous experience. But this winter, even though there was quite a lot of snow in Denmark, he is walking the dogs of his neighbors several times per day because he has the Lommy and feels safe. These neighbors, as informal caregivers, can “see” his position on the map on ISISEMD web portal when he walks the dogs. He feels safe having the Lommy along on the trips. Due to the traumatic experience he had in becoming lost before, he always keeps the Lommy in his pocket.When he is in the home, the cord to charge the device is connected to the Lommy, which remains in the pocket at all times. In this way he never forgets it.

vi. *Cooking Monitor.*

In the end of February, 2011, when the system was under optimization, a formal caregiver received a text message with “Cooking activity has been too long” (that is around 60 min of cooking activity)for one test person. It was afternoon and she called the test person and found out that the woman began to cook, but felt tired and lied down on the coach and fell asleep, forgetting the cooker. When the formal caregiver called the test person on the phone to check if everything was fine, she woke her up and the elderly switched the cooker off. Usually after 60 minutes of cooking, the Carebox would also “tell” the elderly about this alarm, but on this day, the audio feature was turned off due to the testing.

vii. *Out of Bed for Too Long.*

One elderly had several incidents where she has fallen down during the night. Her relative had received the SMS message where it was written that EP has been out of bed too long. The ICG went to her mother’s home first thing in the morning and found her mother fallen down on floor and could not get herself up. The daughter is very happy that she got the text messages, even though she got them during the night.

viii. *Person Left the House.*

One EP is not safe to leave the house by herself anymore and the daughter, as ICG, received text messages from the ISISEMD system that her mother had left the house. The daughter went to her mother’s place and found her walking on the street, confused and without knowing where to go. Particularly in Finland, this service is very important since during the winter it is very cold and dangerous for the elderly to go out of home for an extended period of time.

ix. *Intelligent Front Door.*

Two of the test EPs has started to receive help from local homecare services. The relatives can see on intelligent front door service when the homecare nurse has visited and for how long. The relatives have been very satisfied with this service, because they can be sure that nurse has visited as it had been agreed upon.

Disclaimer

Acknowledgments

The work presented in this paper is partially funded by the ICT PSP EU project "ISISEMD-Intelligent system for independent living and self-care of seniors with cognitive problems or mild dementia." Contract no. ICT-PSP-2-238914, http://www.isisemd.eu [8]. The authors would like to acknowledge also the contributions of their colleagues from the four regions—Anne Abildgaard and D. Flagstad from Municipality of Frederikshavn (Denmark); K. Rääpysjärvi from Municipality of Lappeenranta, Finland; J. Harpur, I. Brown, and N. Magee from Belfast Health and Social care Trust (UK); George Gorgogetas from Municipality of Trikala (Greece) to the user-requirement analysis, definition of the final services from end-user perspective, carrying out the service validation and evaluations, and the contributions of the other partners from the consortium.

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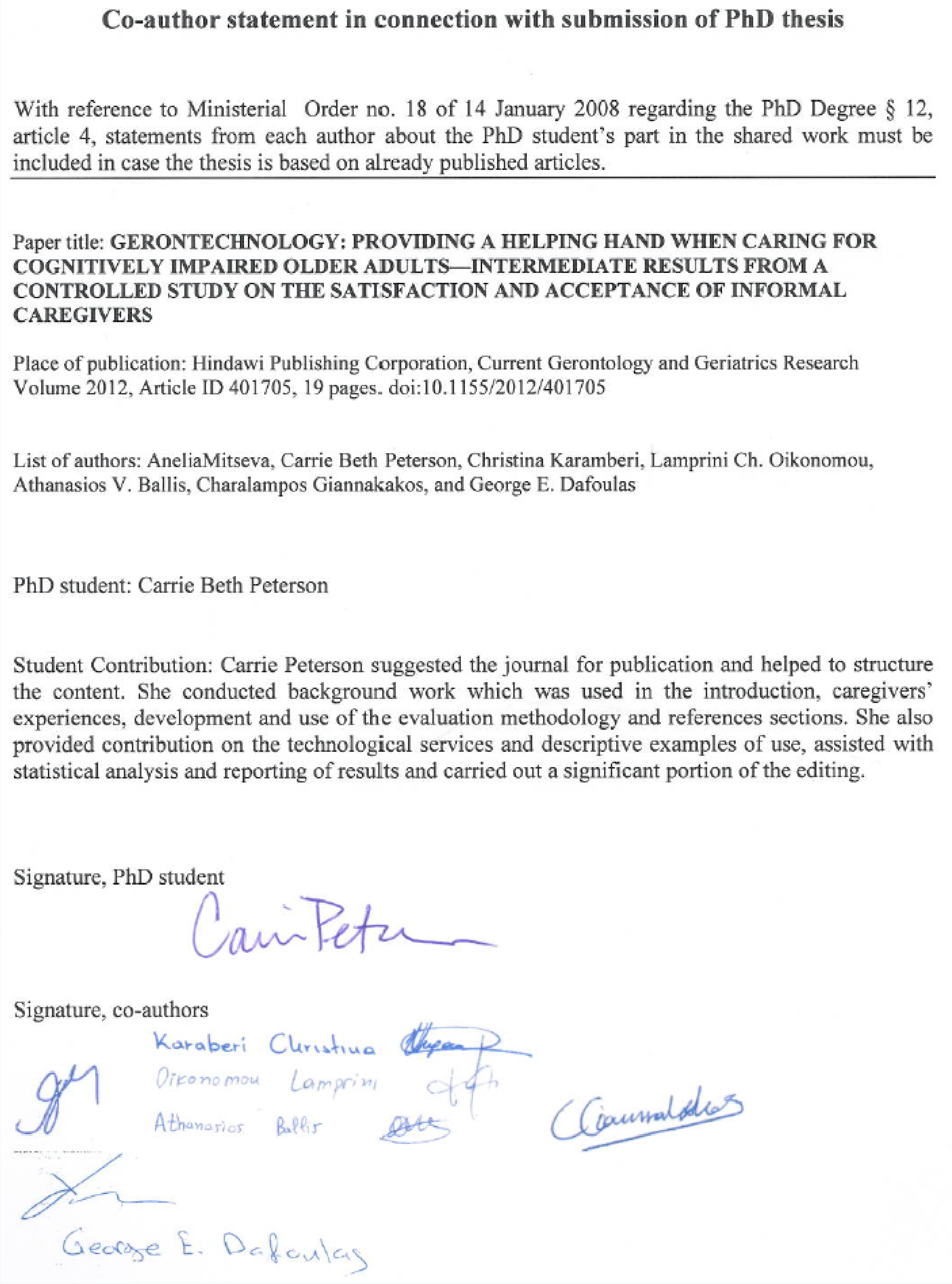

Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **GERONTECHNOLOGY: PROVIDING A HELPING HAND WHEN CARING FOR COGNITIVELY IMPAIRED OLDER ADULTS—INTERMEDIATE RESULTS FROM A CONTROLLED STUDY ON THE SATISFACTION AND ACCEPTANCE OF INFORMAL CAREGIVERS**

Place of publication: Hindawi Publishing Corporation, Current Gerontology and Geriatrics Research Volume 2012, Article ID 401705, 19 pages. doi:10.1155/2012/401705

List of authors: AneliaMitseva, Carrie Beth Peterson, Christina Karamberi, Lamprini Ch. Oikonomou, Athanasios V. Ballis, Charalampos Giannakakos, and George E. Dafoulas

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson suggested the journal for publication and helped to structure the content. She conducted background work which was used in the introduction, caregivers' experiences, development and use of the evaluation methodology and references sections. She also provided contribution on the technological services and descriptive examples of use, assisted with statistical analysis and reporting of results and carried out a significant portion of the editing.

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Paper E: Assessing assistive technology outcomes with dementia

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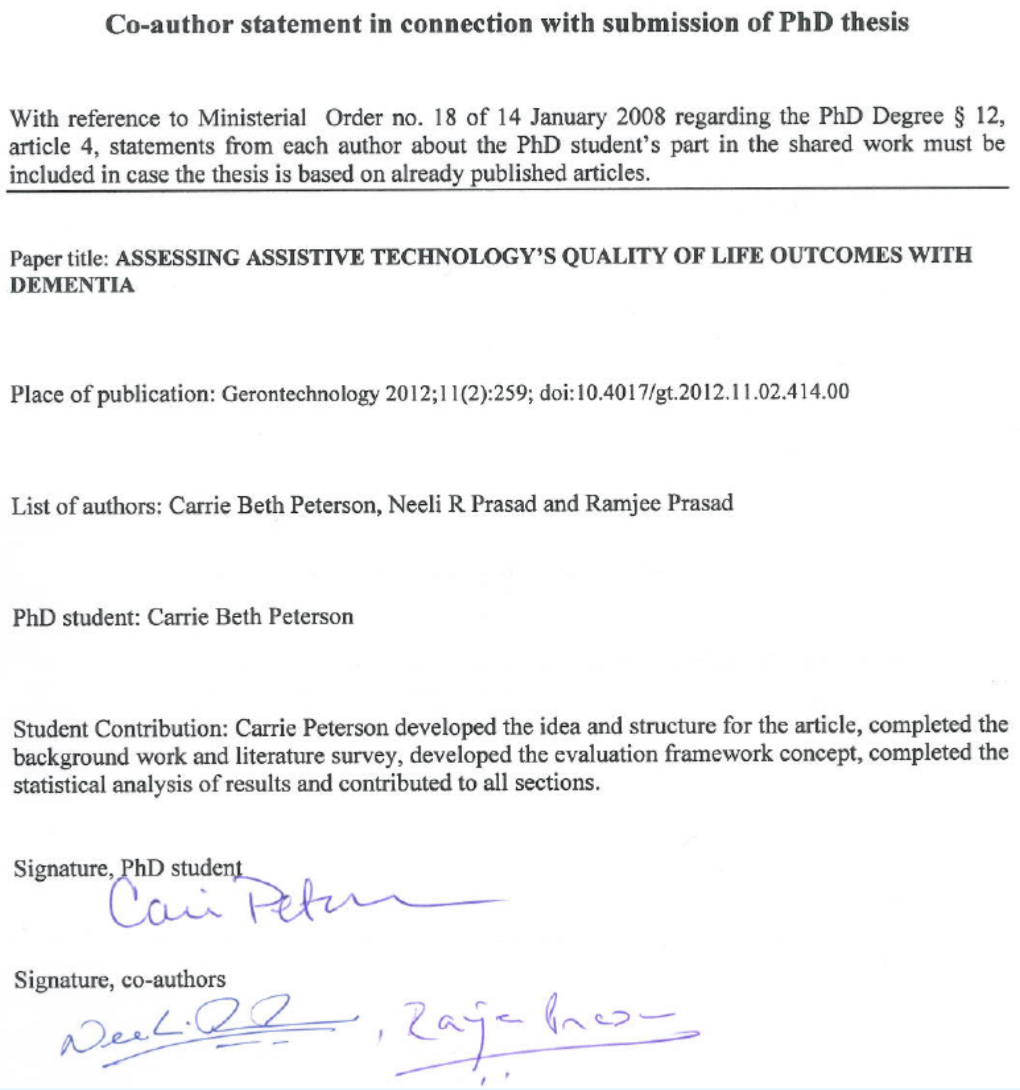
Purpose This article presents a review of the available evaluation of quality of life (QOL) outcomes as a result of assistive technology (AT) interaction among older adults with cognitive impairment and the further development of an outcome assessment framework specific to this area of research. The framework is based on a previous version first proposed by the authors in 2010[1] and results derived from working on the ISISEMD-project[2,3]. **Method** A literature review compiled relevant AT-outcomes assessments specific to QOL-results of dementia interventions, describing strengths and weaknesses. Furthermore, during the course of the ISISEMD-trials, issues arose that highlighted the lack of appropriate assessments for evaluating QOL in dementia with AT-interventions. This needed to be addressed in order to further develop the fields of AT-outcomes measurement, QOL-assessment, and dementia care. The original framework, describing the development and application of an electronic QOL-assessment format incorporating the AT-enhanced environment for those with dementia, aims to close the variance between AT-use and AT-outcomes with empirical demonstration. **Results & Discussion** Results include: (i) Assessment of current outcomes measurement tools and methods; (ii) Analysis of the issues involved in AT-outcomes measurement; and (iii) Description of the framework and its application for dementia AT-outcomes assessment. There is a significant lack of appropriate measurement tools that examine QOL outcomes as a result of AT-interaction in dementia care. Through the use of the proposed framework, researchers and clinicians can better determine which ATs will stimulate the desired intervention outcomes as well as measure their effectiveness. This has implications for dementia care, technology development, socioeconomic benefits and policy.



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **ASSESSING ASSISTIVE TECHNOLOGY'S QUALITY OF LIFE OUTCOMES WITH DEMENTIA**

Place of publication: Gerontechnology 2012;11(2):259; doi:10.4017/gt.2012.11.02.414.00

List of authors: Carrie Beth Peterson, Neeli R Prasad and Ramjee Prasad

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson developed the idea and structure for the article, completed the background work and literature survey, developed the evaluation framework concept, completed the statistical analysis of results and contributed to all sections.

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Paper F: The future of assistive technologies for dementia

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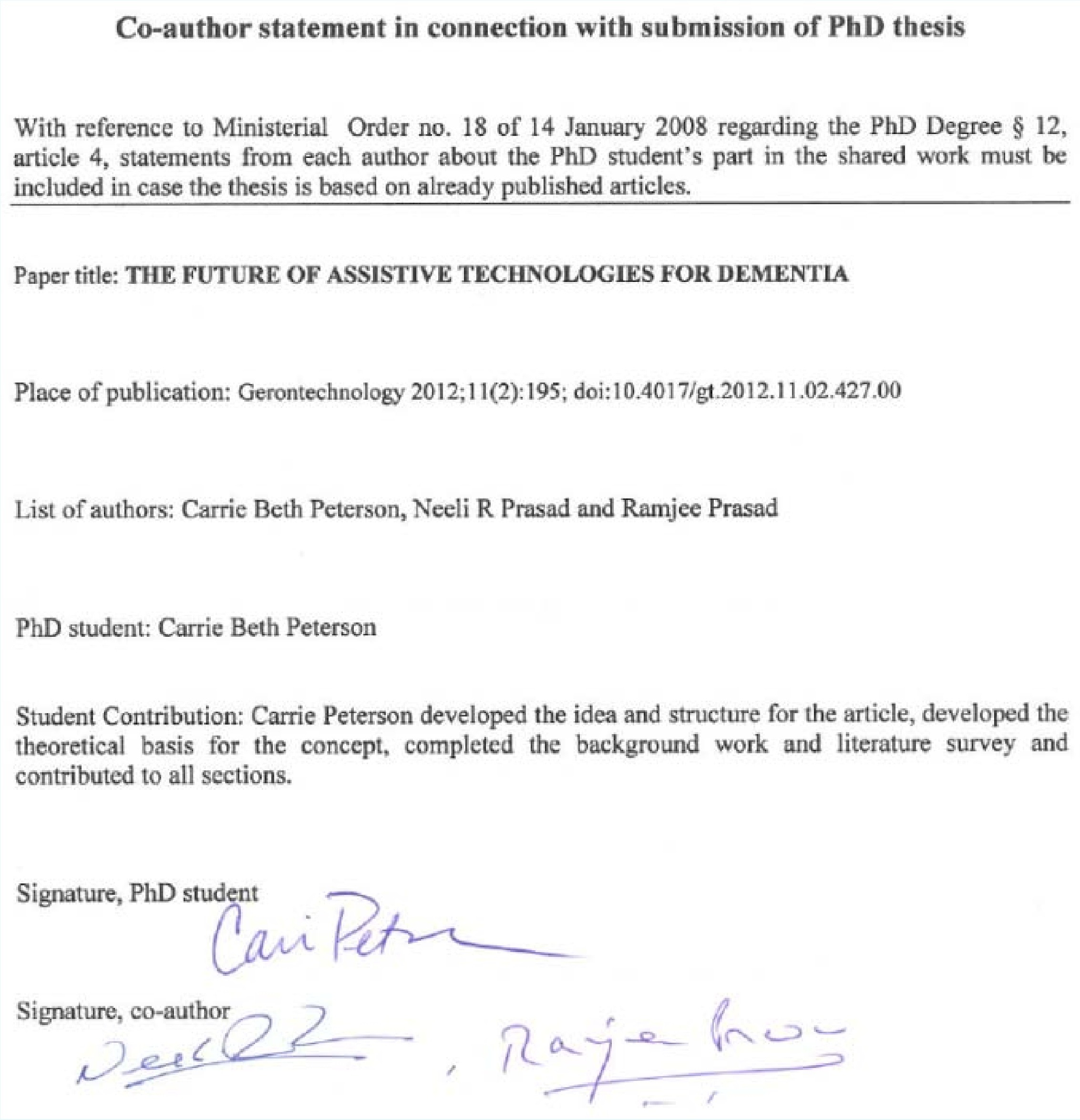
Purpose The use of Assistive Technologies (ATs) for residential dementia care is increasing, yet there is a gap between what individuals want, what developers design, and how outcomes are evaluated. Despite widespread acceptance that ATs improve quality of living (QOL), there is relatively little data to support such claims. This article discusses the current state-of-the-art AT-design, its use and assessment in relation to dementia care and projected future trends that can be incorporated into research now. **Method** By reviewing a history of ATs used in residential dementia care, incorporating societal and healthcare trends and applying theories of science, a futuristic view of AT-development and use is presented. The theoretical foundation is rooted in phenomenology, universal design, aging in place and gerontechnology. This research is supported by results from a European Commission-funded project where ATs were integrated and tested in real life conditions and evaluated qualitatively and quantitatively by older adults with dementia as well as their formal and informal caregivers. **Results & Discussion** The results shows the need for future ATs to be more integrated into the environment, combined with ambient and intelligent technologies, the Internet of Things (IoT), and the potential of cloud computing. They will also become more personalized to individual needs and user requirements.



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **THE FUTURE OF ASSISTIVE TECHNOLOGIES FOR DEMENTIA**

Place of publication: Gerontechnology 2012;11(2):195; doi:10.4017/gt.2012.11.02.427.00

List of authors: Carrie Beth Peterson, Neeli R Prasad and Ramjee Prasad

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson developed the idea and structure for the article, developed the theoretical basis for the concept, completed the background work and literature survey and contributed to all sections.

Signature, PhD student
Cari Pet

Signature, co-author

Paper G: Zarit Burden Interview shows reduction in caregiver burden in European dementia study

Carrie Beth Peterson, *research assistant*[1], Lars Bo Larsen, *associate professor*[1], Poul Svante Eriksen, *associate professor*[2], Ole K Hejlesen, *professor*[3]

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Abstract

Objective: Case-control intervention analysis on the efficacy of telecare services on caregiver burden for informal caregivers of home-dwelling individuals with dementia after 15 months.

Design: Multinational, non-blinded, quasi-experimental, clinical intervention trial (nonpharmacological)

Setting: Homes of individuals with dementia in North Ireland, Denmark, Finland, and Greece

Participants: 31 individuals with dementia and their caregivers are compared to 22 control dyads.

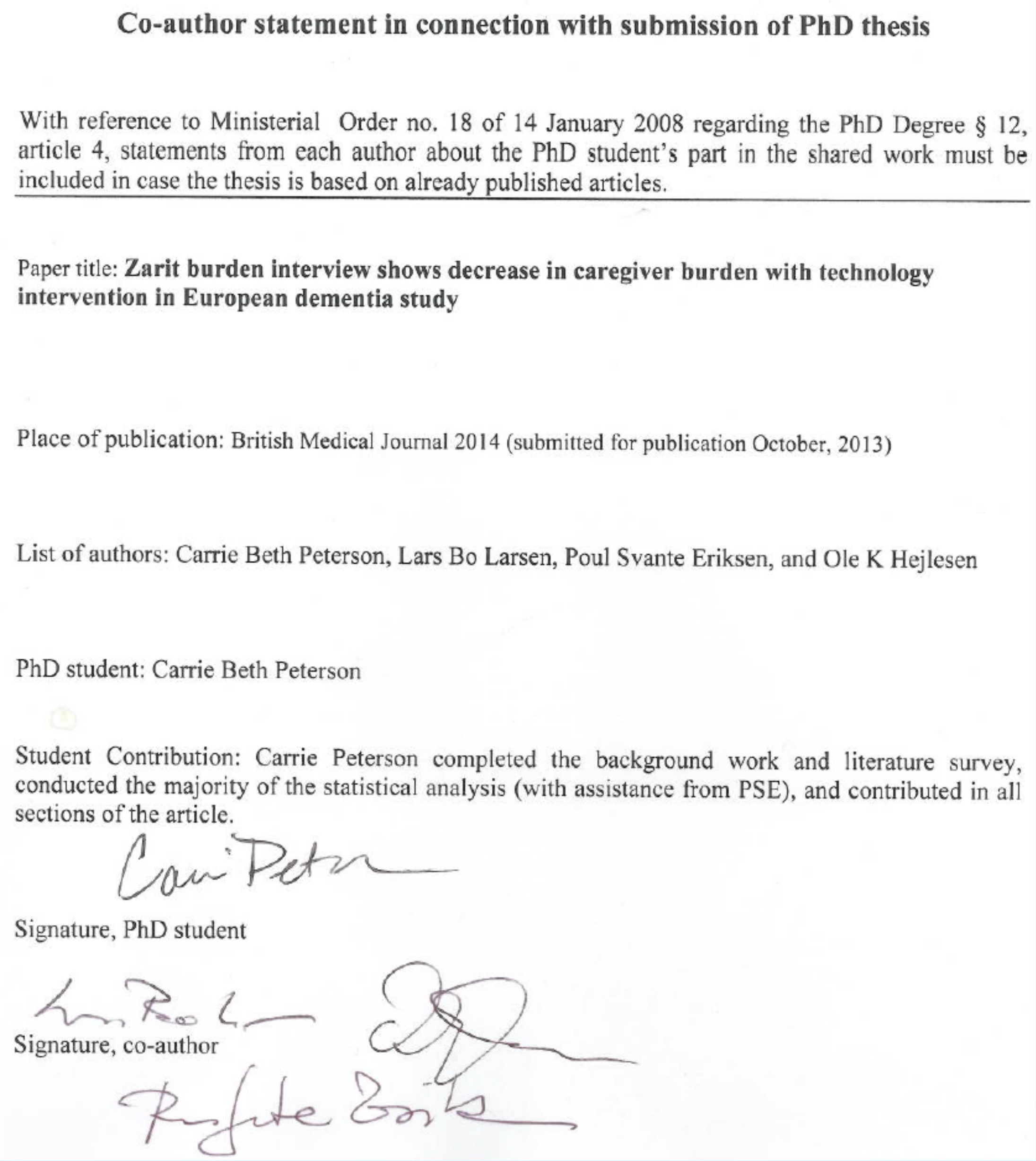
Intervention: A telecare system consisting of domotics with a centralized architecture aimed to support safety, independence, and quality of life, and to reduce caregiver burden through the transfer of tasks and care support.

Main outcome measures: Physical functioning (ADL and IADL), quality of life (QOL-AD and SQLC), and caregiver burden (ZBI). The statistical analysis applied *t*-tests to verify significant differences and Pearson correlations to test for linear relationships within the data, all using 95% Confidence Interval. The focus of this paper is on the outcomes in caregiver burden.

Results: There was a highly significant difference in caregiver burden between the technology intervention and control groups (p=0,03). The intervention group showed a non-significant decrease in caregiver burden (p=0,51) while the control group showed a highly significant increase in caregiver burden (p=0,01).

Conclusion: This study showed that the use of telecare technologies to support dementia care can have significant protective and positive effects for the informal caregivers.

Trial registration: The Phase I clinical intervention trial did not require registration. Trial information can be found for European Commission Competitiveness and Innovation Programme - Information and Communication Technology - Policy Support Programme pilot type B.2008.1.4 project ISISEMD; reference: CIP-ICT-PSP-2-238914. http://www.isisemd.eu/



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published articles.

Paper title: **Zarit burden interview shows decrease in caregiver burden with technology intervention in European dementia study**

Place of publication: British Medical Journal 2014 (submitted for publication October, 2013)

List of authors: Carrie Beth Peterson, Lars Bo Larsen, Poul Svante Eriksen, and Ole K Hejlesen

PhD student: Carrie Beth Peterson

Student Contribution: Carrie Peterson completed the background work and literature survey, conducted the majority of the statistical analysis (with assistance from PSE), and contributed in all sections of the article.

Signature, PhD student

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Paper H: Results from a clinical trial on gerontechnology in dementia care and caregiver quality of life outcomes

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Abstract

Background Informal caregivers for someone with dementia experience stresses due to the intensive nature of the caregiving, often termed “caregiver burden,” and related declines in their quality of life. In this study, the Scale of Quality of Life of Caregivers was used to evaluate the effects on life quality. Assistive technologies were installed in the homes of the patients with dementia and the questionnaires evaluated outcomes of the care intervention.

Methods The SQLC assessment tool was administered at the beginning of the trial, before any care intervention, and again at the conclusion of the 15 month trial. The assessment was given to both the control and intervention groups by professional caregiving staff in each of the 4 European regions.

Results The results of the study show that there is not a significant difference between the intervention and control group outcomes as both show non-significant improvement.

Conclusions The results of this study indicate that using technologies to support dementia caregiving has positive effects for the quality of life of the caregivers, although it does not seem to be significantly better than usual care. There are some issues with the evaluation tools used in research on dementia care and quality of life outcomes and further development is required.

Appendix 2 Dementia types and prevalence

Table 26 Description of the most prevalent types of dementia

Type of dementia	Symptoms	Prevalence
Alzheimer's disease	Plaques (beta-amyloid deposits) and tangles (tau protein) are hallmark symptoms of Alzheimer's. Difficulty recalling names and remembering events, apathy, depression, disorientation, confusion, behavior changes, eventual difficulty speaking, eating, and with mobility.	Up to 80% of individuals with dementia have Alzheimer's disease.
Mixed dementia	Mixed dementia is more than one type of dementia occurring simultaneously, but most patients will have a diagnosis of the type of dementia with the most prevalent symptoms.	Most likely occurring more often than previously thought, it is believed that more than 50% of individuals with dementia actually have coexisting dementias (pathologic evidence only upon autopsy).
Vascular dementia	Vascular dementia is caused by conditions that reduce blood flow to the brain, such as stroke, and cause cell death and by vascular-related conditions like hypertension. Impaired task completion and planning, trouble speaking or understanding others, and difficulty in social situations.	Accounts for 20-30% of dementias.
Dementia with Lewy bodies	Clumps of the protein alpha-synuclein develop in the cortex (the same protein is evident with Parkinson's disease but clumps in a different pattern, which may be why symptoms of the two are similar). Difficulty with recalling and remembering, sleep disturbance, muscle rigidity or spasms similar to those in Parkinson's, confusion, and visual hallucinations.	10-25% of dementia cases are Dementia with Lewy bodies.
Parkinson's disease dementia	Parkinson's dementia symptoms are similar to Lewy bodies but with the alpha-synuclein protein clumps developing in the substantia nigra. Problems with muscles and movements, impaired memory and judgment, inability to pay attention or complete a task, difficulty with visual information or hallucinations, and sleep disturbances.	Around 2% of adults over 65 have Parkinson's, and up to 85% of those develop Parkinson's disease dementia.
Mild Cognitive Impairment	Mild cognitive impairment involves cognitive changes that are serious enough to be noticed but not serious enough to meet diagnostic criteria for dementia.	Between 10-20% of adults over age 65 are estimated to have mild cognitive impairment; those individuals have a higher risk of developing Alzheimer's disease or another dementia.
Frontotemporal dementia	Progressive cell degeneration in the frontal or temporal lobes causes this group of disorders (including progressive supranuclear palsy, primary progressive aphasia, Pick's disease, and behavioral variant Frontotemporal dementia). Impaired judgment and planning, changes in behavior, difficulty with language, and changes in muscle functions are broadly common symptoms.	10-15% of dementias are of this type. Additionally, Frontotemporal dementia typically develops in one's 50s or 60s; up to 50% of dementias in individuals under age 65 are this type.
Posterior Cortical Atrophy	There is a gradual, progressive degeneration of the posterior cortex (the outer layer in the back of the brain). This area of the brain is associated with visual processing, so symptoms include difficulties with reading and judging distances, disorientation, and some experience hallucinations.	Prevalence is estimated at 15%; however, it is yet unknown if this is a unique form of dementia or a variant of another type as brain changes resemble Dementia with Lewy bodies and Creutzfeldt-Jakob disease, and the diseased area of the brain has plaques and tangles similar to those in Alzheimer's disease.

Creutzfeldt-Jakob disease	Misfolded prion protein in the brain causes this rapidly fatal brain disorder (prion disease), resulting in behavior changes, confusion, and impaired memory, judgment, and muscle coordination.	Only about 1 in 1 million develops this type of dementia, of which there are 3 subtypes: Sporadic type makes up 85%, Familial type accounts for up to 15%, and Infectious type causes around 1% of Creutzfeldt-Jakob disease.
Normal pressure hydrocephalus	Excess cerebrospinal fluid accumulates in the brain's ventricles. Difficulties in thinking, problems with walking, and urinary incontinence are the three most prevalent symptoms.	The symptoms are commonly similar to other brain disorders so specific prevalence is unknown.
Huntington's disease	A single defective gene on chromosome 4 causes this progressive brain disorder. Severe declines in thinking and reasoning skills, mood changes, and involuntary movements are hallmark symptoms.	The gene defect is dominant, so anyone who inherits it from a parent with the disease will eventually develop it, most commonly between ages 30-50.
(Wernicke-) Korsakoff syndrome	It is most commonly a result of alcohol abuse but can also result from AIDS, dialysis, poor nutrition, chronic infection, or other conditions. Severe deficiency in vitamin B1 (thiamine) causes the chronic memory disorder. Problems in learning and memory (both short- and long-term) are the main symptoms.	It is up to the doctor to evaluate the cause of the symptoms as there is no specific procedure to confirm diagnosis. It is unknown how many people have Korsakoff syndrome.
Chronic Traumatic Encephalopathy	Cognitive changes, difficulty learning and remembering, impaired thinking, planning, and judgment skills, and decreased organization of thoughts are common symptoms. These may continue to develop even years after the injury occurred.	Evidence over the past few decades have linked repeated traumatic brain injuries, such as those sustained in boxing or American football, vehicle accidents, shockwaves from explosions, and falls with an increased risk of dementia. Traumatic brain injury has been shown to increase beta-amyloid levels and deposits of tau, the proteins associated with Alzheimer's disease.
Down Syndrome	People with Down syndrome are born with an extra copy of chromosome 21, causing developmental issues and health problems. Reduced interest, behavior problems, coordination changes, and other overall changes to functioning and personality may be more common than memory problems.	Individuals with Down syndrome typically live until age 60; around 75% of those who do live to 65 or older are have Alzheimer's disease or another dementia that is very similar. Autopsy studies show that almost 100% of people with Down syndrome have plaques and tangles by age 40, yet not all develop symptoms.

Appendix 3 Methods to diagnose dementias

Table 27 Description of the most common methods used for the diagnosis of dementias

Diagnostic type	Examples	How they are performed	What is identified	Success rate
Histopathological evidence	Autopsy or biopsy	The brain is examined to determine symptoms of and type of dementia.	Medical professionals can determine clinical pathology of the type of dementia based on changes seen in the brain.	Viewed as the gold standard in dementia diagnostics.
Diagnostic manual	DSM – the Diagnostic and Statistical Manual of Mental Disorders is published by the American Psychological Association, providing a nomenclature and standard criteria for mental disorder classification [329]. Intended for research, it is mostly used in the US by clinicians, researchers, for health insurance, pharmaceutical companies, and for legal processes. However, it should be used with caution, as nearly 75% of the current panel members have financial ties to the pharmaceutical industry [330].	Professionals should have extensive clinical training in order to use the DSM to assess the symptoms of dementia to determine diagnosis.	Dementia can be identified and differentiated from other mental disorders. The DSM is primarily concerned with (superficial) symptoms rather than underlying pathology. There is a risk for over-medicalization; for example, normal cognitive aging is now classified as "Minor Neurocognitive Disorder," giving the implication of (abnormal) pathological conditions.	Alzheimer's disease [331]: 51% sensitivity 97% specificity 66% accuracy Vascular Dementia [332]: 50% sensitivity 84% specificity
Statistical classification	ICD – the International Classification of Disease and Health Related Problems is produced by the WHO [333]. It is the official clinical diagnostic tool for mental disorders in the US, but is used more widely in Europe, although it has become more common in the US in recent years, i.e. all HIPPA covered entities. It is used to classify health issues for health records, death certificates, epidemiology, mortality and morbidity statistics, reimbursement, and resource allocation.	Trained professionals learn the coding and IT system for the ICD, which is also available for self-study on the WHO website.	Diagnostic information on diseases and health problems are statistically-based (as opposed to symptom-based in the DSM), and can be classified, stored, and retrieved. It is not limited to mental disorders, so provides a more realistic picture of comorbidities and context of health issues.	Vascular Dementia [332]: 20% sensitivity 94% specificity

Diagnostic type	**Examples**	**How they are performed**	**What is identified**	**Success rate**
Clinical criteria	NINCDS-ADRDA – National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association are widely used clinical criteria to diagnose dementias [334]. The criteria are recommended by the UK NHS and the American Academy of Neurology.	Clinical diagnosis of Alzheimer's disease are presented in three documents: (1) core clinical criteria regarding AD dementia, (2) core clinical criteria regarding MCI due to AD, and (3) recommendations regarding preclinical AD. 1 and 2 are for clinical diagnosis while 3 is intended only for research purposes.	They specify eight cognitive domains that may be impaired in Alzheimer's disease: memory, language, perceptual skills, attention, constructive abilities, orientation, problem solving, and functional abilities.	Probable Alzheimer's disease [286]: 81% sensitivity 70% specificity
Cognitive testing – these test the expressed functioning of cognitive abilities	MMSE – the Mini-Mental State Examination is one of the most commonly used assessments for cognitive functioning and dementia screening [285]. This assessment is included in Appendix 5.	Trained professionals administer the assessment, which takes around 10 minutes to complete.	Gross cognitive functioning and changes are tested via i.e. orientation, recall, and language use and comprehension.	Alzheimer's disease [335]: 93% sensitivity 46% specificity 77% accuracy Frontotemporal Dementia [336]: 58% sensitivity 88% specificity 73% accuracy Dementia (by cut off score of 26) [337]: 80% sensitivity 96% specificity Mild Cognitive Impairment [338]: 65% sensitivity 89% specificity 83% accuracy
	MoCA – the Montreal Cognitive Assessment is used to detect milder impairments, particularly for early identification as it is sensitive to mild changes [288]. This assessment is included in Appendix 5.	The assessment takes 5-10 minutes to complete and is designed to be administered even by lay people.	Fine cognitive impairment and changes are assessed through i.e. orientation, memory and recall, visuospatial reasoning, and language use and comprehension	Frontotemporal Dementia [336]: 78% sensitivity 98% specificity 88% accuracy Mild Cognitive Impairment [338]: 97% sensitivity 60% specificity 91% accuracy Alzheimer's disease [287]: 100% sensitivity 87% specificity

Diagnostic type	Examples	How they are performed	What is identified	Success rate
Structural imaging – these allow to look at the structure of the brain for dementia-related changes	MRI – Magnetic Resonance Imaging employs powerful magnetic fields and radio waves to look at the soft tissues of the body, such as the brain.	Patients lay or stand in an MRI machine and an electromagnetic field is used to align atomic nuclei in the body.	Detailed images show changes in the brain tissue, such as atrophy.	Alzheimer's disease [339]: 76,5% sensitivity 94% specificity
	CT – Computed Tomography utilizes computer-processed x-rays to generate "sliced," or tomographic, images of the body.	All CT scans involve ionizing radiation from x-rays and around 50% of CT scans involve using a radiocontrast agent to visualize vessels and changes in tissue. CT scans of the head can perceive infarctions, tumors, hemorrhage, edema, and other brain maladies.	CT scan data can be used to examine (brain) structure and detect tissue damage, based on which areas block the x-rays.	Alzheimer's disease [339]: 80% sensivity 87% specificity
Functional imaging – allows for examining the functioning of the brain and cognitive processes	PET – Positron Emission Tomography uses a radioactive tracer isotope to emit a positron that will interact with an electron, creating a burst of light which is recorded.	PET data collected by itself can be quite poor (i.e. scatter or random events), so it is often combined with CT or MRI imaging. The biologic pathway can be traced, meaning that changes in brain functioning due to molecular biology can be detected before anatomic changes occur.	The flow of blood to different parts of the brain is measured, and this can distinguish Alzheimer's from other dementias.	Alzheimer's disease [340]: 93% sensitivity 80% specificity 87% accuracy Dementia [341]: 94% sensitivity 78% specificity 92% accuracy
	fMRI – Functional MRI involves repeated scans to track the movement of blood through the brain and map neural activity in the brain.	The repeated scans in fMRI allow for a functional image of the brain, as opposed to the static image through MRI. Can be task-related MRI (i.e. recall a phrase) or resting state MRI.	Blood flow in the brain is mapped to identify areas used in i.e. listening, speaking, and sensing, and how they are affected by the dementia.	Alzheimer's disease [342]: 72% sensitivity 78% specificity 89% accuracy
Molecular imaging – examines the movement of specific molecules in the brain to determine dementia prevalence and type	SPECT – Single Photon Emission Computed Tomography uses gamma rays to make 2D cross-sectional slices of the brain and to provide 3D information when manipulated [343].	Patients are injected with a gamma-emitting tracer, which attaches to the brain and can be detected with the gamma-camera that is rotated around the patient. SPECT provides accurate localization in 3D space, but images typically have lower resolution than PET scans.	Regional cerebral blood flow and brain metabolism are measured to diagnose and differentiate dementias.	Alzheimer's disease [335]: 63% sensitivity 75% specificity 67% accuracy

Diagnostic type	Examples	How they are performed	What is identified	Success rate
Biomarkers – biological markers of dementia can be found in fluid samples from the individuals	CSF – Cerebrospinal Fluid is assessed for changes in protein levels.	Patients undergo a lumbar puncture, where spinal fluid is extracted. Beta-amyloid peptide and tau levels are studied.	Levels of the two proteins are measured to detect Alzheimer's disease. However, changes in these proteins cannot be correlated to levels of cognition (i.e. MMSE).	Alzheimer's disease [344]: 85% sensitivity 84% specificity Mild Cognitive Impairment (incipient Alzheimer's disease) [344]: 95% sensitivity 83% specificity
	Genetic – the apolipoprotien E epsilon 4 (APOE-e4) allele is the largest (known) genetic risk factor for Alzheimer's disease.	Blood or tissue samples from the patients are used to test the genomic DNA for the presence of the APOE genotype.	There are 3 primary uses of genetic testing for Alzheimer's disease: Predicting in cognitively healthy individuals Additional diagnostic in individuals with dementia Selecting individuals with dementia for therapy (including research)	Alzheimer's disease [345]: 82,5% sensitivity 44% specificity

Table 28 Classification and diagnosis of dementias according to the DSM [329] and ICD [333]

<table>
<tr><th></th><th>DSM-IV-TR</th><th>ICD-10</th></tr>
<tr><td>Classification</td><td><i>Delirium, Dementia, and Amnestic and Other Cognitive Disorders</i></td><td><i>Mental and Behavioral Disorders - Organic and Symptomatic Mental Disorders</i></td></tr>
<tr><td>Definition</td><td>An overall decline in intellectual function, most commonly including difficulties with language, simple calculations, planning and judgment, and motor (muscular movement) skills as well as loss of memory. This definition is established by the pattern of cognitive loss and does not distinguish a prognosis as dementia can become more severe, remain unvarying or become less severe.</td><td>Used as diagnostic criteria for research</td></tr>
<tr><td>Diagnosis</td><td>The essential feature of a dementia diagnosis is the development of multiple cognitive deficits that include memory impairment and one or more of the following: aphasia, apraxia, agnosia or executive functioning.</td><td>The decline should be objectively verified by obtaining a reliable history from an informant, supplemented, if possible, by neuropsychological tests or quantified cognitive assessments.</td></tr>
<tr><td>Threshold for diagnosis</td><td>Disturbances must be severe enough to cause problems in the person's daily life and that they must represent a decline from a previously higher level of functioning</td><td>The decline should be present for at least 6 months and severity, with mild impairment as the threshold for diagnosis. Deterioration from a previously higher level of performance should be established.</td></tr>
<tr><td>Predominant symptoms</td><td>A significant destabilization of the person’s memory in learning new information or recalling formerly learned information.</td><td>A decline in memory, which is most evident in the learning of new information, although the recall of previously learned information may be also affected.</td></tr>
<tr><td></td><td colspan="2">Aphasia is a class of language disorder involving a loss of language functions (remembering, speaking, reading or writing words). It can be expressed by the person using general or vague terms such as “that,” “thing,” or “there” because they have difficulties in recalling the exact name or word they are looking for. The impairment applies to both verbal and non-verbal material.</td></tr>
<tr><td></td><td colspan="2">Apraxia is a disorder of motor planning that affects the ability to carry out deliberate actions such as moving an object or buttoning clothing.</td></tr>
<tr><td></td><td colspan="2">Agnosia is characterized by the inability to identify or discern objects, people, sounds, shapes or scents. Despite no change in sensory functions, the brain loses the ability to make sense of the information and identify; it is not uncommon for those with severe agnosia to be unable to recognize close family or even their own faces.</td></tr>
<tr><td></td><td>Problems with executive functioning, such as loss of the ability to make plans, carry out a sequence of actions, make appropriate choices and assess circumstances. For example, a person with dementia may have difficulties following a procedure of dressing in clothes or wear inappropriate clothing for the weather.</td><td>Evidence of damage to other higher cortical functions. A decline in other cognitive abilities characterized by deterioration in judgment and thinking, such as planning and organizing, and in the general processing of information.</td></tr>
<tr><td></td><td>In addition to cognitive changes, the symptoms of dementia may also include personality and behavioral changes and emotional instability.</td><td>A decline in emotional control or motivation, or a change in social behavior, manifest as at least one of the following:
1) emotional liability;
2) irritability;
3) apathy;
4) coarsening of social behavior.</td></tr>
</table>

Appendix 4 Dementia treatments

Table 29 Examples of treatments for dementia symptoms

Treatment type	Name	Use	Benefits	Adverse side effects	Other
Pharmacology	Acetylcholinesterase inhibitors [346]	These medications have been developed to impede or address changes in the brain that are associated with early and middle stages of Alzheimer's disease. They work by increasing the amount of acetylcholine, which helps messages to travel around the brain. People with Alzheimer's disease have a shortage of this chemical.	Some people find these drugs lessen their symptoms for a while. Possible benefits include improvements in motivation, anxiety levels, confidence, daily living, memory and thinking.	Side effects often include loss of appetite, nausea, vomiting, and diarrhea.	These drugs are sometimes given to people with mixed dementia or dementia with Lewy bodies. These drugs aren't suitable for people with Frontotemporal dementia, who may be given antidepressant drugs for some of their symptoms. A person with vascular dementia will usually be prescribed drugs to treat underlying conditions, such as hypertension or heart problems.
	N-Methyl-D-aspartate (NMDA) receptor blockers [347]	This medication is for use in the later stages of Alzheimer's disease. There are often high levels of glutamate (natural substance) in the brains of individuals with Alzheimer's disease and this medication protects the brain cells by blocking NMDA-type glutamate receptors.	NMDA receptor blockers work to temporarily slow the progression of symptoms in the middle and later stages of Alzheimer's disease and dementia with Lewy bodies. It may also help with agitation or aggressive behaviour.	NMDA receptor blockers usually have fewer side effects, but can still cause dizziness, headaches, drowsiness, insomnia, hypertension, and constipation.	
	Selective Serotonin Reuptake Inhibitors [348]	SSRIs reduce depression or anxiety and are prescribed to treat vascular dementia or Parkinson's dementia, particularly in the early stages of dementia.	These antidepressant drugs change the chemical levels in the brain by inhibiting serotonin reuptake in cells. They often help to control neuropsychiatric symptoms.	Common side effects can include appetite and weight changes, fatigue, tremor, difficulty concentrating, nausea, vivid or strange dreams, sleep changes, and increased suicidal thoughts.	Some research shows that common antidepressants don't work as well for people with dementia as for those without dementia.

Treatment type	Name	Use	Benefits	Adverse side effects	Other
Non-pharmacological Interventions	Exercise (Aerobic, Strength training) [244]	Exercise increases the body's natural functioning and can be a form of rehabilitative therapy.	Exercise has protective effects against further decline. Regular exercise can improve behavior, physical functioning, reduce depression, and can improve cognitive functioning.	Doctors should be consulted before starting an exercise routine to rule out or minimize risk of injury due to cardiac or physical exertion.	Group exercise classes also provides an opportunity for socialization.
	Music therapy [254]	Music is played for or by the person with dementia.	Music therapy has been found to calm, soothe, and engage individuals with dementia.		
	Aromatherapy [349]	Specific aromas are used to elicit certain responses, such as relaxation or alertness.	Lemon balm and lavender have been particularly beneficial in dementia treatment.	The oils can be irritating to the eyes, nose, and mouth if too concentrated.	
	Animal-assisted therapy [350]	Trained animals and therapists interact with the individual.	It can be directed behavior, such as brushing the animal to practice gross motor skills, or free form interaction.	Individuals may have allergies or aversions to animals.	
	Patient and family education [351]	Individuals and families can receive education on dementia and symptom management (prognosis, treatment plans, safety considerations and environmental adjustments, financial and legal actions to take, and care support options).	Patients have the opportunity to make their wishes known to family and all engage in a discussion on the diagnosis and what it will entail.	Difficult, sensitive, or uncomfortable family issues can arise.	

Treatment type	Name	Use	Benefits	Adverse side effects	Other
	Talking therapy [351]	Counselors listen to problems in a non-judgmental and supportive way. They support people to talk about their difficulties and identify solutions. Talking therapies, such as counseling or psychotherapy, give people the chance to speak in confidence to a qualified professional about problems or issues that might be bothering them. They might help someone to come to terms with a diagnosis and identify ways to live well with dementia. Talking therapies may also help with symptoms of depression or anxiety. Talking therapies typically involve regular sessions with a therapist, either one-to-one or sometimes in a group. They can be face-to-face, over the phone or online. Some people will have just one session while others will have therapy that continues for many months.	Psychotherapists help people to understand how their personalities and life experiences influence relationships, thoughts, feelings and behavior. Understanding this can make it easier for people to deal with difficulties. Psychotherapy may help to treat depression, anxiety and problematic behavior in people with dementia. Family therapy can also be helpful to resolve problems arising due to changes in relationships.	Difficult, sensitive, or uncomfortable family issues can arise.	There are several different types of psychotherapy. One of the most common types is cognitive behavioral therapy (CBT).
	Cognitive training or therapy [351]	The activities can be done alone, one-on-one, or in groups. Cognitive activities can include Cognitive Stimulation Therapy (CST), Cognitive Behavioral Therapy (CBT), word or number puzzles, and current events for orientation. CBT usually involves between five and 20 sessions. A carer might attend the sessions too so they can then help the person with dementia to use the techniques at home.	Cognitive stimulation approaches have improved mental abilities and quality of life, including memory, reasoning, and ADLs. CBT aims to help people make changes to how they think (cognition) and what they do (behavior). CBT suggests ways of focusing on the here and now.	Individuals may become agitated if overstimulated.	CBT is widely used to treat depression and anxiety. There is growing evidence that it can also help people with dementia and depression.

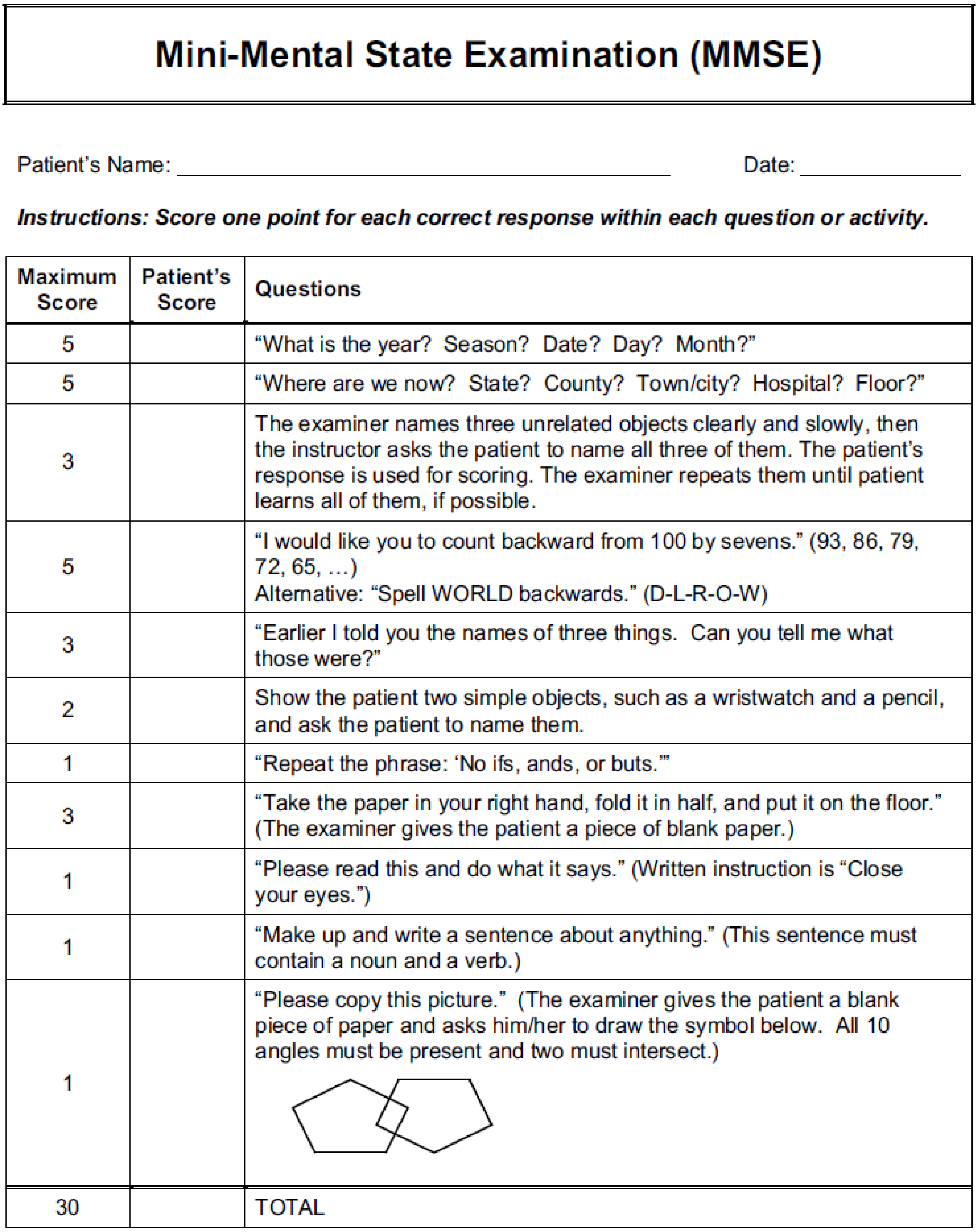
Treatment type	Name	Use	Benefits	Adverse side effects	Other
	Reminiscence therapy and life story work [352]	This type of therapy involves talking about things and people from the past, often using photos, scrap books, artifacts from their past, or music as cues.	There is evidence that this type of therapy can improve mood, well-being, and mental abilities such as memory. Through talking about who they are, individuals with dementia help others to focus on them as a person and not their dementia.	Discussing loved ones who have passed may cause some temporary negative emotional-behavioral responses.	Techniques like this are popular because they draw on early memories, which people with dementia tend to retain best.
Gerontechnology Interventions [200]	Home automation	A range of technologies in the home can automate functions to ensure safety and security.	The individual can be supported by appliances automatically shutting off after use or lights activated by motion sensors. Someone (caregiver or authorities) will be notified if there is an emergency situation in the home, such as wandering outdoors or a fire.	False alarms and system instability can induce worry and foster lack of trust in the technology.	
	Interactive devices	Devices such as robotics, electronic photo albums or puzzles, or surfing the internet can encourage cognitive functioning and interaction with the environment.	Using devices that are designed for individuals with dementia can provide stimulation, entertainment, and support the enjoyment of activities.	Some may become frustrated or discouraged if the technology highlights deficiencies rather than abilities.	Introducing new technologies in later stages of dementia may require a longer learning time.
	GPS	If the individual with dementia has a GPS-enabled device with them when they leave the home, they can be located by caregivers or authorities.	The main benefit is locating the individual if they would wander from the home or otherwise become lost.	There is a risk of breach in data confidentiality.	

Appendix 5 Assessment tools used in the research

Table 30 Overview of the assessments used

Variable	Tools	Example of what is evaluated	Score range	Score interpretation
Cognition	MMSE	Changes in cognition, memory, orientation, and visuo-construction	0 to30	≥26 = Normal 19-25,5 = Mild impairment 10-18,5 = Moderate impairment 0-9,5 = Severe impairment
	MoCA	Milder changes in cognition, attention, abstraction, and delayed recall	0 to30	≥ 26 = Normal 19-25,5 = Mild impairment 10-18,5 = Moderate impairment 0-9,5 = Severe impairment
Physical functioning and independence	ADL	Bathing, eating, continence, and basic physical functioning independence	0 to 6	Higher score = higher independence 3-4 = moderate dependence 0-2 = severe dependence
	IADL	Food preparation, medication management, and higher level physical functioning independence	0 to 8	Higher score = higher independence
Quality of life	QOL-AD	QOL of person with dementia, health, living situation, and ability to do things for fun	13 to 52	Higher score = higher quality of life
	SQLC	QOL of the caregiver, professional activities, social and leisure activities, and caregiving responsibilities	0 to 149	141-149 = Effective adaptation of the caregiver 100-140 = Mild effect on QOL 86-99 = Moderate effect on QOL <85 = Severe effect on QOL
Caregiver burden	12-item ZBI	Personal strain and role strain	0 to 48	Higher score means higher burden ≥17 = clinically significant burden

Assessment 1: Mini-Mental State Examination (MMSE)

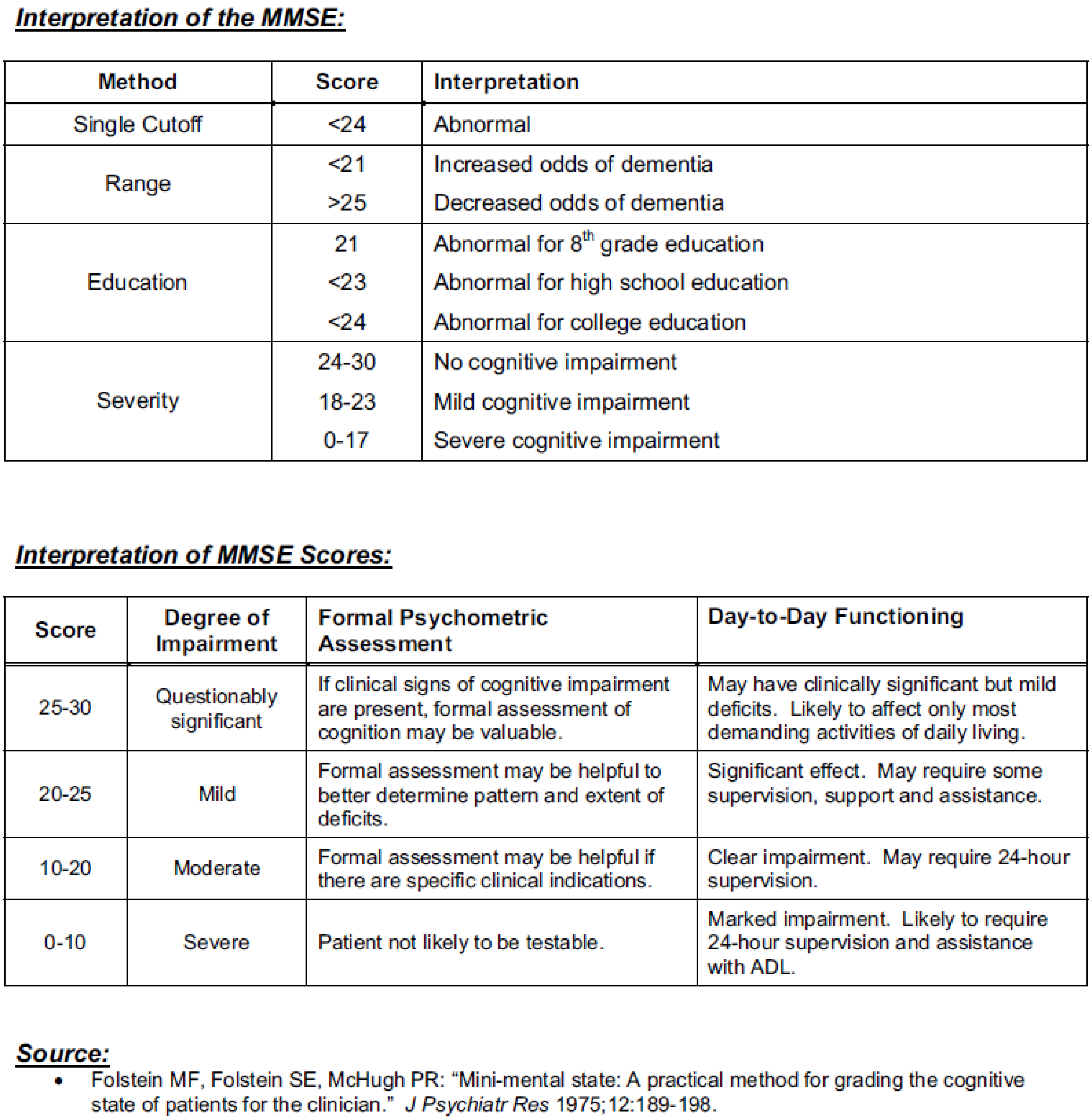


Mini-Mental State Examination (MMSE)

Patient's Name: ______________________________ Date: ____________

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	**Patient's Score**	**Questions**
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, …) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)
30		TOTAL



Interpretation of the MMSE:

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21	Increased odds of dementia
	>25	Decreased odds of dementia
Education	21	Abnormal for 8th grade education
	<23	Abnormal for high school education
	<24	Abnormal for college education
Severity	24-30	No cognitive impairment
	18-23	Mild cognitive impairment
	0-17	Severe cognitive impairment

Interpretation of MMSE Scores:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-25	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-20	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-10	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

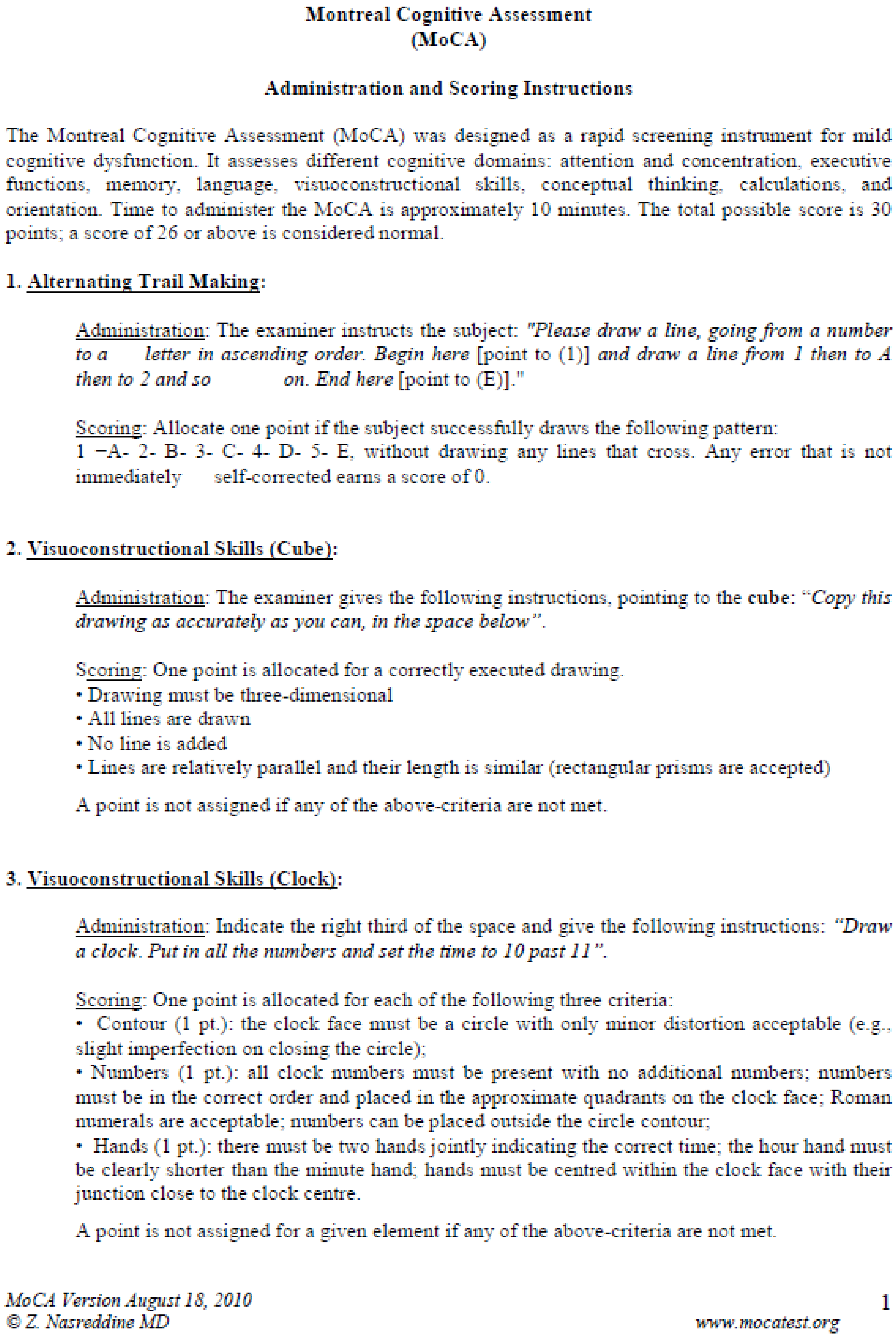
Source:

- Folstein MF, Folstein SE, McHugh PR: "Mini-mental state: A practical method for grading the cognitive state of patients for the clinician." *J Psychiatr Res* 1975;12:189-198.

Table 31 Median scores by age and education level on the Mini-Mental State Examination [353]

Years of age	Education level			
	4th grade	8th grade	High School	College
18-24	22	27	29	29
25-29	25	27	29	29
30-34	25	26	29	29
35-39	23	26	28	29
40-44	23	27	28	29
45-49	23	26	28	29
50-54	23	27	28	29
55-59	23	26	28	29
60-64	23	26	28	29
65-69	22	26	28	29
70-74	22	25	27	29
75-79	21	25	27	28
80-84	20	25	25	27
85+	19	23	26	27

Assessment 2: Montreal Cognitive Assessment (MoCA)



Montreal Cognitive Assessment
(MoCA)

Administration and Scoring Instructions

The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal.

1. Alternating Trail Making:

Administration: The examiner instructs the subject: *"Please draw a line, going from a number to a letter in ascending order. Begin here* [point to (1)] *and draw a line from 1 then to A then to 2 and so on. End here* [point to (E)]."

Scoring: Allocate one point if the subject successfully draws the following pattern: 1 −A- 2- B- 3- C- 4- D- 5- E, without drawing any lines that cross. Any error that is not immediately self-corrected earns a score of 0.

2. Visuoconstructional Skills (Cube):

Administration: The examiner gives the following instructions, pointing to the **cube**: *"Copy this drawing as accurately as you can, in the space below"*.

Scoring: One point is allocated for a correctly executed drawing.
- Drawing must be three-dimensional
- All lines are drawn
- No line is added
- Lines are relatively parallel and their length is similar (rectangular prisms are accepted)

A point is not assigned if any of the above-criteria are not met.

3. Visuoconstructional Skills (Clock):

Administration: Indicate the right third of the space and give the following instructions: *"Draw a clock. Put in all the numbers and set the time to 10 past 11"*.

Scoring: One point is allocated for each of the following three criteria:
- Contour (1 pt.): the clock face must be a circle with only minor distortion acceptable (e.g., slight imperfection on closing the circle);
- Numbers (1 pt.): all clock numbers must be present with no additional numbers; numbers must be in the correct order and placed in the approximate quadrants on the clock face; Roman numerals are acceptable; numbers can be placed outside the circle contour;
- Hands (1 pt.): there must be two hands jointly indicating the correct time; the hour hand must be clearly shorter than the minute hand; hands must be centred within the clock face with their junction close to the clock centre.

A point is not assigned for a given element if any of the above-criteria are not met.

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4. Naming:

Administration: Beginning on the left, point to each figure and say: *"Tell me the name of this animal"*.

Scoring: One point each is given for the following responses: (1) lion (2) rhinoceros or rhino (3) camel or dromedary.

5. Memory:

Administration: The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: *"This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them"*. Mark a check in the allocated space for each word the subject produces on this first trial. When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a second time with the following instructions: *"I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time."* Put a check in the allocated space for each word the subject recalls after the second trial.
At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, *"I will ask you to recall those words again at the end of the test."*

Scoring: No points are given for Trials One and Two.

6. Attention:

Forward Digit Span: Administration: Give the following instruction: *"I am going to say some numbers and when I am through, repeat them to me exactly as I said them"*. Read the five number sequence at a rate of one digit per second.

Backward Digit Span: Administration: Give the following instruction: *"Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order."* Read the three number sequence at a rate of one digit per second.

Scoring: Allocate one point for each sequence correctly repeated, (*N.B.*: the correct response for the backwards trial is 2-4-7).

Vigilance: Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: *"I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If I say a different letter, do not tap your hand"*.

Scoring: Give one point if there is zero to one errors (an error is a tap on a wrong letter or a failure to tap on letter A).

Serial 7s: Administration: The examiner gives the following instruction: *"Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop."* Give this instruction twice if necessary.

Scoring: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correction subtraction, 2 points for two-to-three correct subtractions, and 3 points if the participant successfully makes four or five correct subtractions. Count each correct subtraction of 7 beginning at 100. Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction. For example, a participant may respond "92 – 85 – 78 – 71 – 64" where the "92" is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the item would be given a score of 3.

7. Sentence repetition:

Administration: The examiner gives the following instructions: *"I am going to read you a sentence. Repeat it after me, exactly as I say it* [pause]: ***I only know that John is the one to help today."*** Following the response, say: *"Now I am going to read you another sentence. Repeat it after me, exactly as I say it* [pause]: ***The cat always hid under the couch when dogs were in the room."***

Scoring: Allocate 1 point for each sentence correctly repeated. Repetition must be exact. Be alert for errors that are omissions (e.g., omitting "only", "always") and substitutions/additions (e.g., "John is the one who helped today;" substituting "hides" for "hid", altering plurals, etc.).

8. Verbal fluency:

Administration: The examiner gives the following instruction: *"Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready?* [Pause] *Now, tell me as many words as you can think of that begin with the letter F.* [time for 60 sec]. *Stop."*

Scoring: Allocate one point if the subject generates 11 words or more in 60 sec. Record the subject's response in the bottom or side margins.

9. Abstraction:

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: *"Tell me how an orange and a banana are alike"*. If the subject answers in a concrete manner, then say only one additional time: *"Tell me another way in which those items are alike"*. If the subject does not give the appropriate response *(fruit)*, say, *"Yes, and they are also both fruit."* Do not give any additional instructions or clarification. After the practice trial, say: *"Now, tell me how a train and a bicycle are alike"*. Following the response, administer the second trial, saying: *"Now tell me how a ruler and a watch are alike"*. Do not give any additional instructions or prompts.

Scoring: Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable:

Train-bicycle = means of transportation, means of travelling, you take trips in both;

Ruler-watch = measuring instruments, used to measure.

The following responses are **not** acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.

10. Delayed recall:

Administration: The examiner gives the following instruction: *"I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember."* Make a check mark (√) for each of the words correctly recalled spontaneously without any cues, in the allocated space.

Scoring: **Allocate 1 point for each word recalled freely without any cues.**

Optional:

Following the delayed free recall trial, prompt the subject with the semantic category cue provided below for any word not recalled. Make a check mark (√) in the allocated space if the subject remembered the word with the help of a category or multiple-choice cue. Prompt all non-recalled words in this manner. If the subject does not recall the word after the category cue, give him/her a multiple choice trial, using the following example instruction, *"Which of the following words do you think it was, NOSE, FACE, or HAND?"*

Use the following category and/or multiple-choice cues for each word, when appropriate:

FACE:	category cue: part of the body	multiple choice: nose, face, hand
VELVET:	category cue: type of fabric	multiple choice: denim, cotton, velvet
CHURCH:	category cue: type of building	multiple choice: church, school, hospital
DAISY:	category cue: type of flower	multiple choice: rose, daisy, tulip
RED:	category cue: a colour	multiple choice: red, blue, green

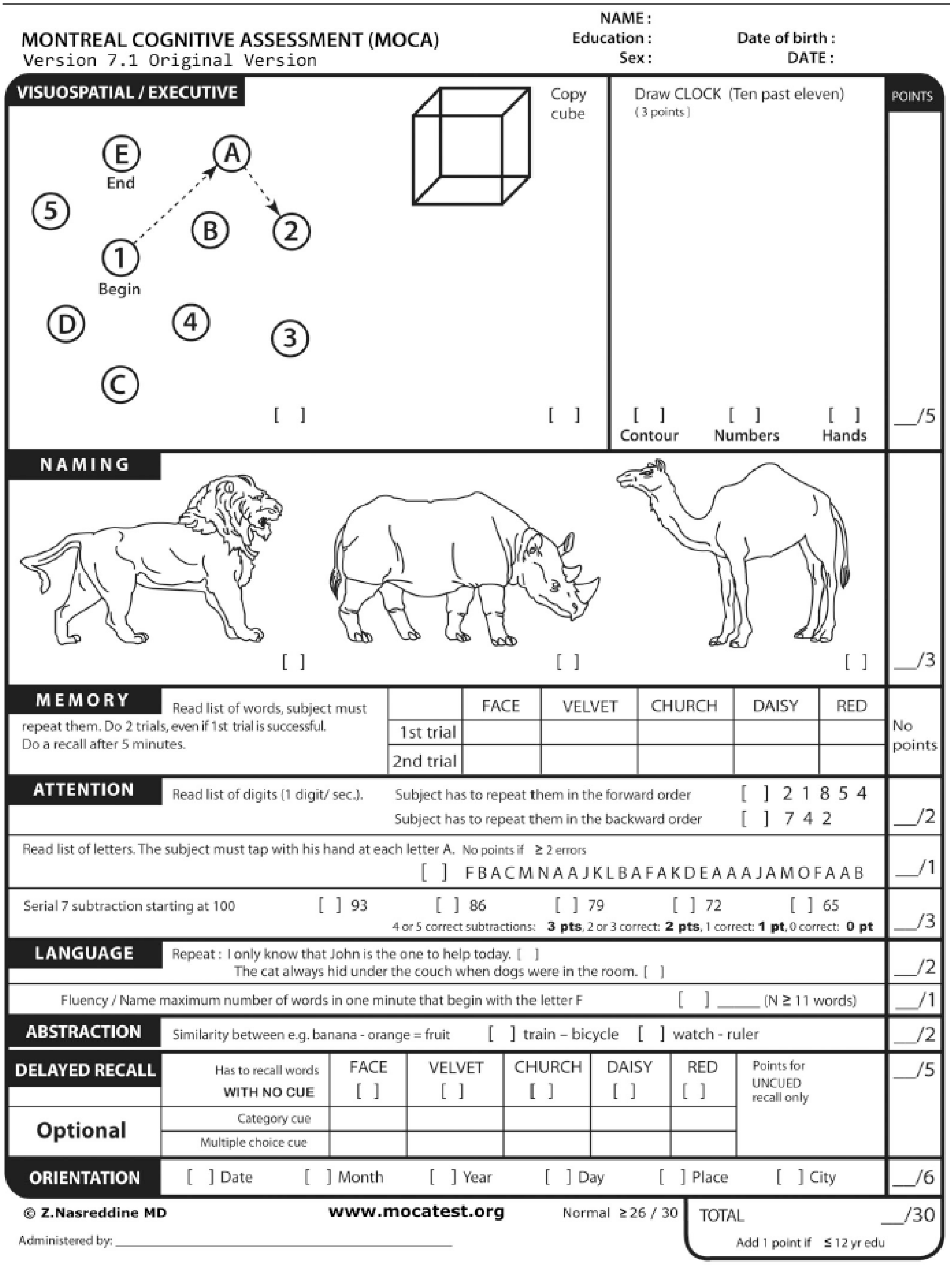
Scoring: **No points are allocated for words recalled with a cue.** A cue is used for clinical information purposes only and can give the test interpreter additional information about the type of memory disorder. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.

11. Orientation:

Administration: The examiner gives the following instructions: "Tell me the date today". If the subject does not give a complete answer, then prompt accordingly by saying: *"Tell me the [year, month, exact date, and day of the week]."* Then say: *"Now, tell me the name of this place, and which city it is in."*

Scoring: Give one point for each item correctly answered. The subject must tell the exact date and the exact place (name of hospital, clinic, office). No points are allocated if subject makes an error of one day for the day and date.

TOTAL SCORE: Sum all subscores listed on the right-hand side. Add one point for an individual who has 12 years or fewer of formal education, for a possible maximum of 30 points. A final total score of 26 and above is considered normal.



MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE	Copy cube	Draw CLOCK (Ten past eleven) (3 points)		POINTS
[ ]	[ ]	[ ] Contour	[ ] Numbers	[ ] Hands	__/5

NAMING [ ] [ ] [ ] __/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED	
1st trial						No points
2nd trial						

ATTENTION Read list of digits (1 digit/ sec.).
Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2 __/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] FBACMNAAJKLBAFAKDEAAAJAMOFAAB __/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** __/3

LANGUAGE Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ] __/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words) __/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler __/2

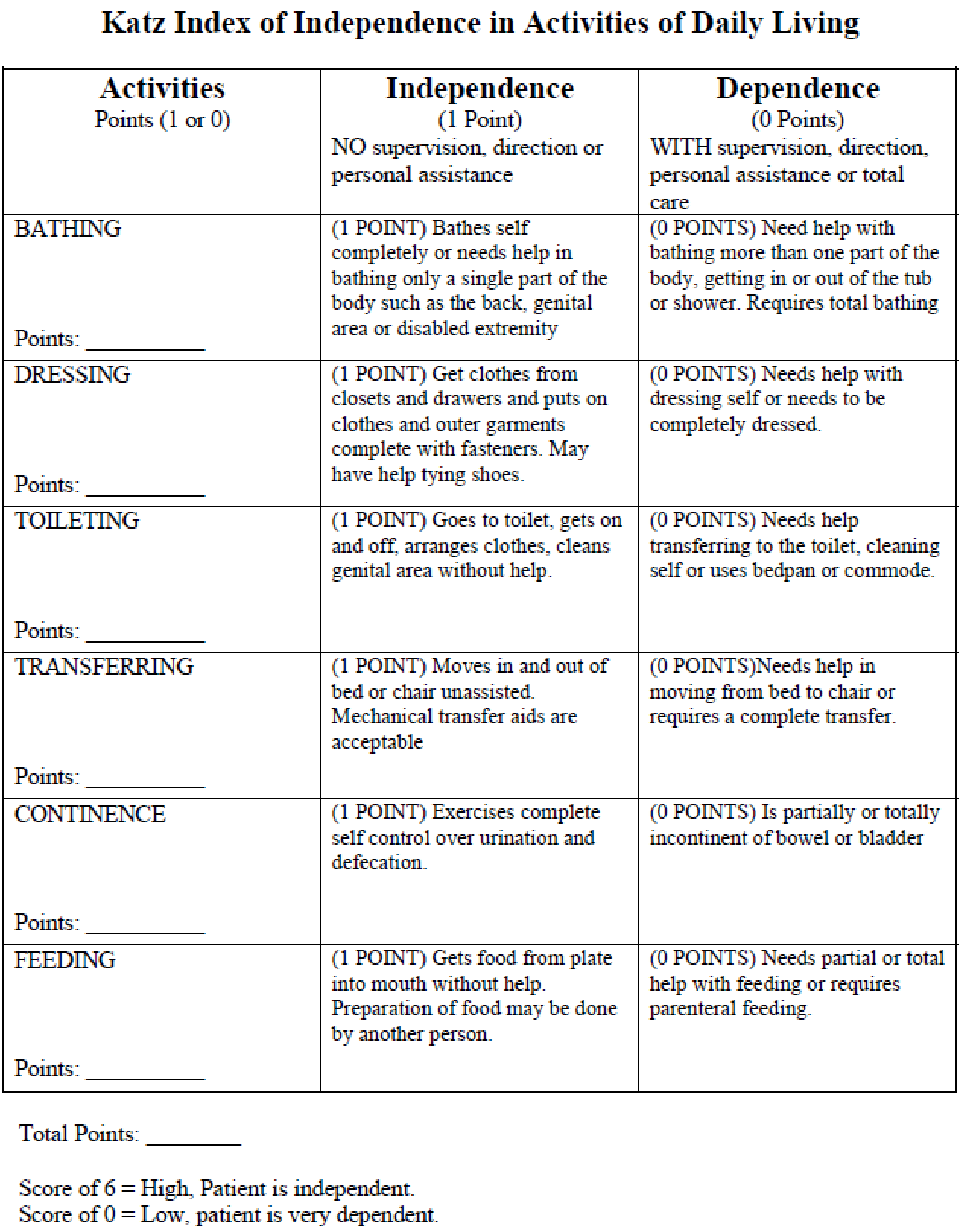
DELAYED RECALL	Has to recall words WITH NO CUE	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only	__/5
Optional	Category cue							
	Multiple choice cue							

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City __/6

www.mocatest.org Normal ≥26 / 30 TOTAL __/30
Add 1 point if ≤ 12 yr edu

Administered by: ____________________

Assessment 3: Activities of Daily Living (ADL)



Katz Index of Independence in Activities of Daily Living

Activities Points (1 or 0)	**Independence** (1 Point) NO supervision, direction or personal assistance	**Dependence** (0 Points) WITH supervision, direction, personal assistance or total care
BATHING Points: ___________	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity	(0 POINTS) Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing
DRESSING Points: ___________	(1 POINT) Get clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING Points: ___________	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING Points: ___________	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable	(0 POINTS)Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE Points: ___________	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder
FEEDING Points: ___________	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.

Total Points: _________

Score of 6 = High, Patient is independent.
Score of 0 = Low, patient is very dependent.

Assessment 4: Instrumental Activities of Daily Living (IADL)

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)

M.P. Lawton & E.M. Brody

A. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers, etc.	1
2. Dials a few well-known numbers	1
3. Answers telephone but does not dial	1
4. Does not use telephone at all.	0

B. Shopping

1. Takes care of all shopping needs independently	1
2. Shops independently for small purchases	0
3. Needs to be accompanied on any shopping trip.	0
4. Completely unable to shop.	0

C. Food Preparation

1. Plans, prepares and serves adequate meals independently	1
2. Prepares adequate meals if supplied with ingredients	0
3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet.	0
4. Needs to have meals prepared and served.	0

D. Housekeeping

1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help")	1
2. Performs light daily tasks such as dish-washing, bed making	1
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.	1
4. Needs help with all home maintenance tasks.	1
5. Does not participate in any housekeeping tasks.	0

E. Laundry

1. Does personal laundry completely	1
2. Launders small items; rinses stockings, etc.	1
3. All laundry must be done by others.	0

F. Mode of Transportation

1. Travels independently on public transportation or drives own car.	1
2. Arranges own travel via taxi, but does not otherwise use public transportation.	1
3. Travels on public transportation when accompanied by another.	1
4. Travel limited to taxi or automobile with assistance of another.	0
5. Does not travel at all.	0

G. Responsibility for own medications

1. Is responsible for taking medication in correct dosages at correct time.	1
2. Takes responsibility if medication is prepared in advance in separate dosage.	0
3. Is not capable of dispensing own medication.	0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income.	1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	1
3. Incapable if handling money.	0

Assessment 5: Quality of Life-Alzheimer's disease (QOL-AD)

Quality of Life-AD
Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. **First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.**

2. **How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?**
4. **How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?**

5. **How about your memory? Would you say it is poor, fair, good, or excellent?**

6. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

7. **How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom

they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. It there is no one appropriate, or the participant is unsure, score the item as missing. If the participant's rating is of their relationship with someone other than their spouse, note this and record the relationship in the comments section.

8. **How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**

9. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?**

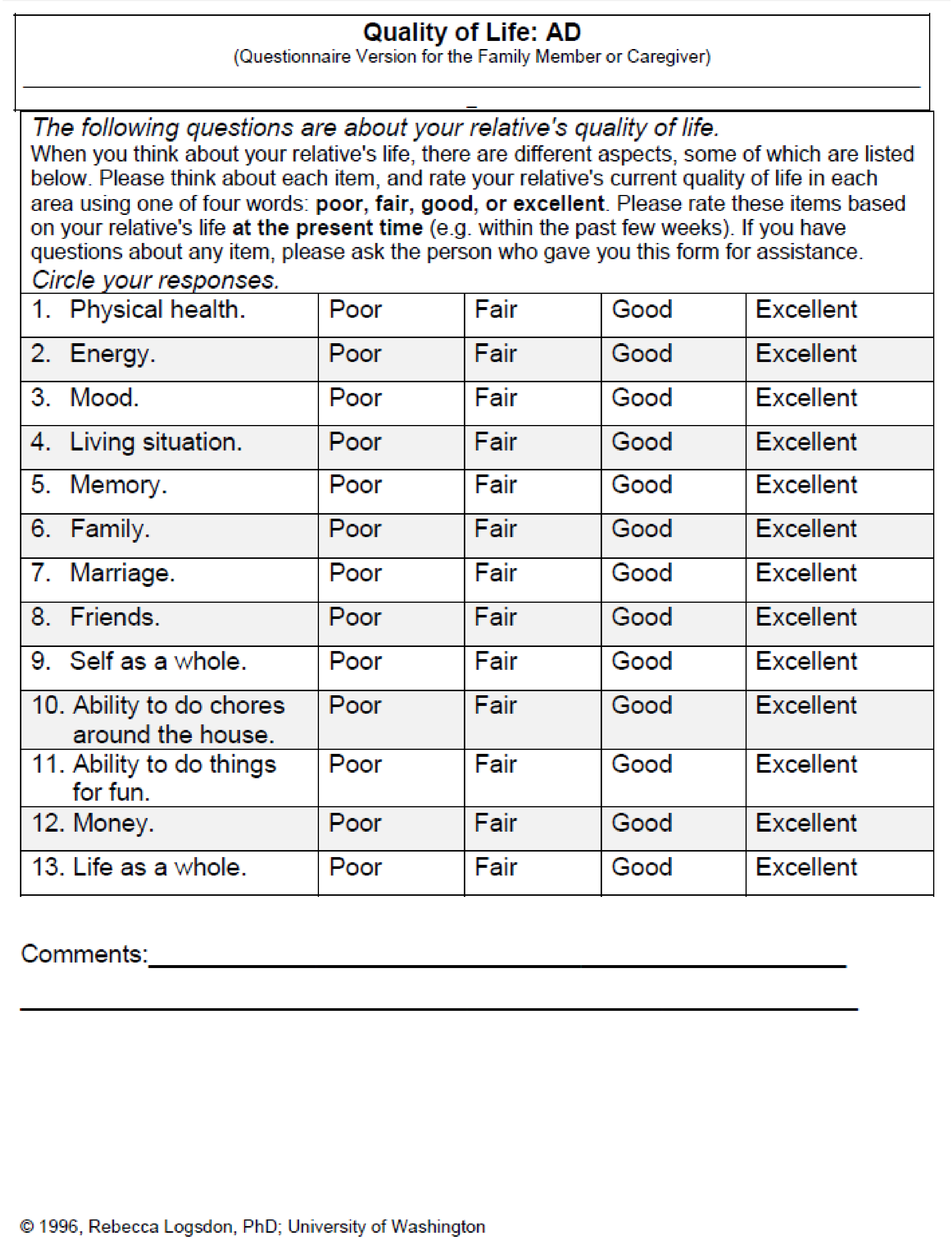
10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?**

11. **How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?**

12. **How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent?** If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.

13. **How would you describe your life as a whole? When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?**

SCORING INSTRUCTIONS FOR THE QOL:
Points are assigned to each item as follows: poor=1, fair=2, good=3, excellent=4.
The total score is the sum of all 13 items.



Quality of Life: AD

(Questionnaire Version for the Family Member or Caregiver)

The following questions are about your relative's quality of life.
When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: **poor, fair, good, or excellent**. Please rate these items based on your relative's life **at the present time** (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.
Circle your responses.

1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments:____

____

Quality of Life: AD

(Interview Version for the person with dementia)

Interviewer administer according to standard instructions.
Circle responses.

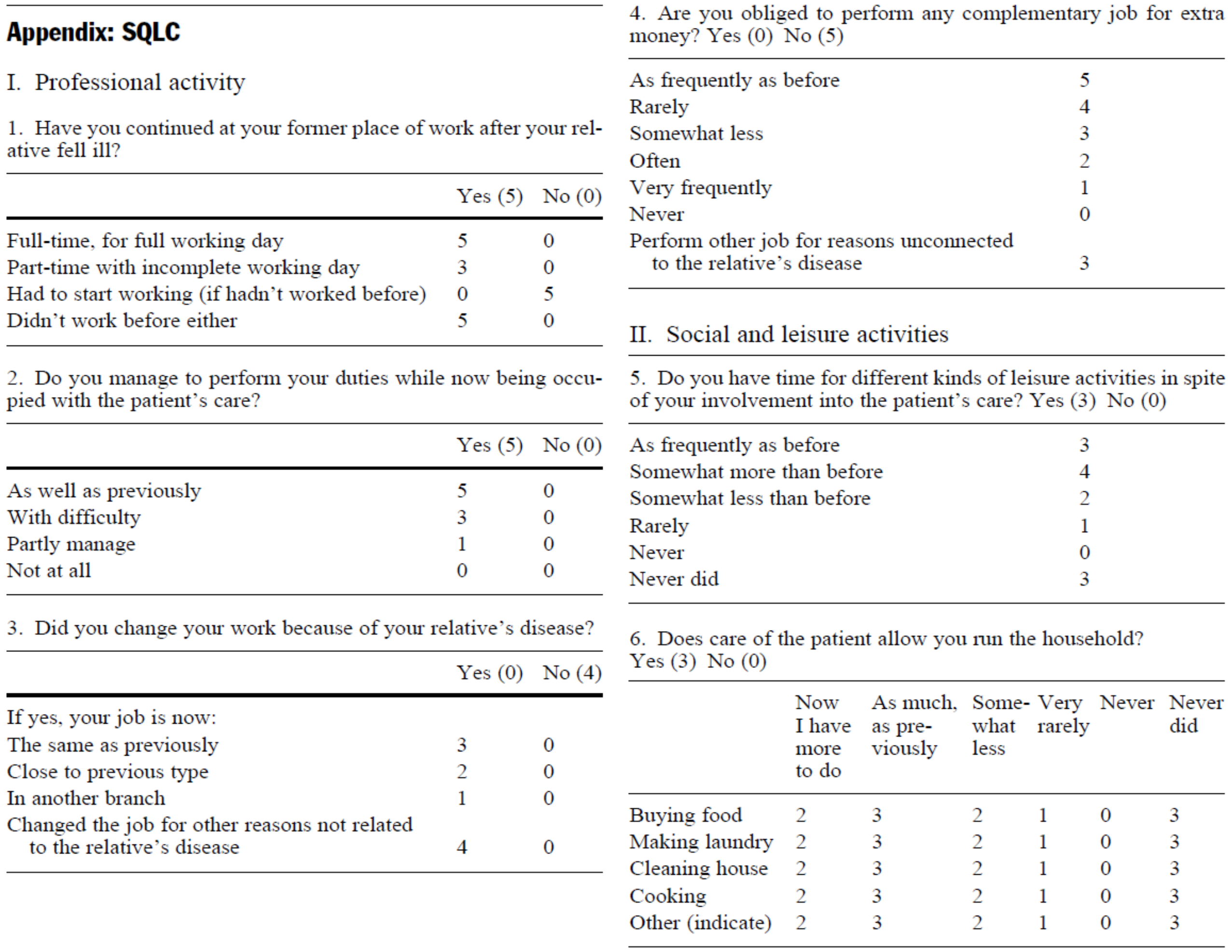
1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments:____

____

____

Assessment 6: Scale of Quality of Life of Caregivers (SQLC)



Appendix: SQLC

I. Professional activity

1. Have you continued at your former place of work after your relative fell ill?

	Yes (5)	No (0)
Full-time, for full working day	5	0
Part-time with incomplete working day	3	0
Had to start working (if hadn't worked before)	0	5
Didn't work before either	5	0

2. Do you manage to perform your duties while now being occupied with the patient's care?

	Yes (5)	No (0)
As well as previously	5	0
With difficulty	3	0
Partly manage	1	0
Not at all	0	0

3. Did you change your work because of your relative's disease?

	Yes (0)	No (4)
If yes, your job is now:		
The same as previously	3	0
Close to previous type	2	0
In another branch	1	0
Changed the job for other reasons not related to the relative's disease	4	0

4. Are you obliged to perform any complementary job for extra money? Yes (0) No (5)

As frequently as before	5
Rarely	4
Somewhat less	3
Often	2
Very frequently	1
Never	0
Perform other job for reasons unconnected to the relative's disease	3

II. Social and leisure activities

5. Do you have time for different kinds of leisure activities in spite of your involvement into the patient's care? Yes (3) No (0)

As frequently as before	3
Somewhat more than before	4
Somewhat less than before	2
Rarely	1
Never	0
Never did	3

6. Does care of the patient allow you run the household? Yes (3) No (0)

	Now I have more to do	As much, as previously	Somewhat less	Very rarely	Never	Never did
Buying food	2	3	2	1	0	3
Making laundry	2	3	2	1	0	3
Cleaning house	2	3	2	1	0	3
Cooking	2	3	2	1	0	3
Other (indicate)	2	3	2	1	0	3

7. Does care of patient allow you to give a hand to you parents and other relatives? Yes (3) No (0)

More frequently than before as I have now stopped work	4
As frequently than before	3
Somewhat less frequently	2
Very rarely	1
Never	0
Never did	3
More frequently than before as now it is may responsibility	2

8. Do you continue to discuss family plans and problems with your ill relative? Yes (3) No (0)

More often than before	4
As often as before	3
A little less often than before	2
Very rarely	1
Never	0
Never did before	3

9. Does the care of our relative let you to continue to attend to the needs of your children or the grandchildren as well as you did before? Yes (3) No (0)

	More frequently than before as I have now stopped work	As frequently than before	Somewhat less frequently	Very rarely	Never	Never did	More frequently than before as now it is may responsibility
To control and help children in scholarship	4	3	2	1	0	3	2
To take children to school, to sport activities or for a walk	4	3	2	1	0	3	2
To take children to theaters, museums, etc.	4	3	2	1	0	3	2
Other (indicate)	4	3	2	1	0	3	2

III. Responsibilities of the care-giver to help the patient in his everyday living

10. Does the regular everyday care and attention to the chronically disabled person make you depressed? Yes (0) No (3)

The mood is the same as before	5
Continuous depression (a week or more)	3
Stable depression with weight loss and insomnia	0
Depression for reasons unconnected with relative's disease	5

11. Can the patient stay at home by himself while the family members are out or away? Yes (3) No (0)

Without assistance he is able to:	Always	Sometimes	Never
Dress	2	1	0
Make the bed	2	1	0
Warm up food	2	1	0
Take food left for him (wrapped up or in container)	2	1	0

12. Does your patient need assistance when using public transport or car-driving? Yes (0) No (3)

Never needs assistance	3
Somewhat more often than before	2
Very often	1
Always needs assistance	0
Needed assistance before disease started	3

13. Can your patient regularly take the prescribed medicine by himself? Yes (3) No (2)

Always	2
Sometimes	1
Never	0

14. Can your relative take a bath without assistance? Yes (3) No (0)

Always	2
Sometimes	1
Never	0

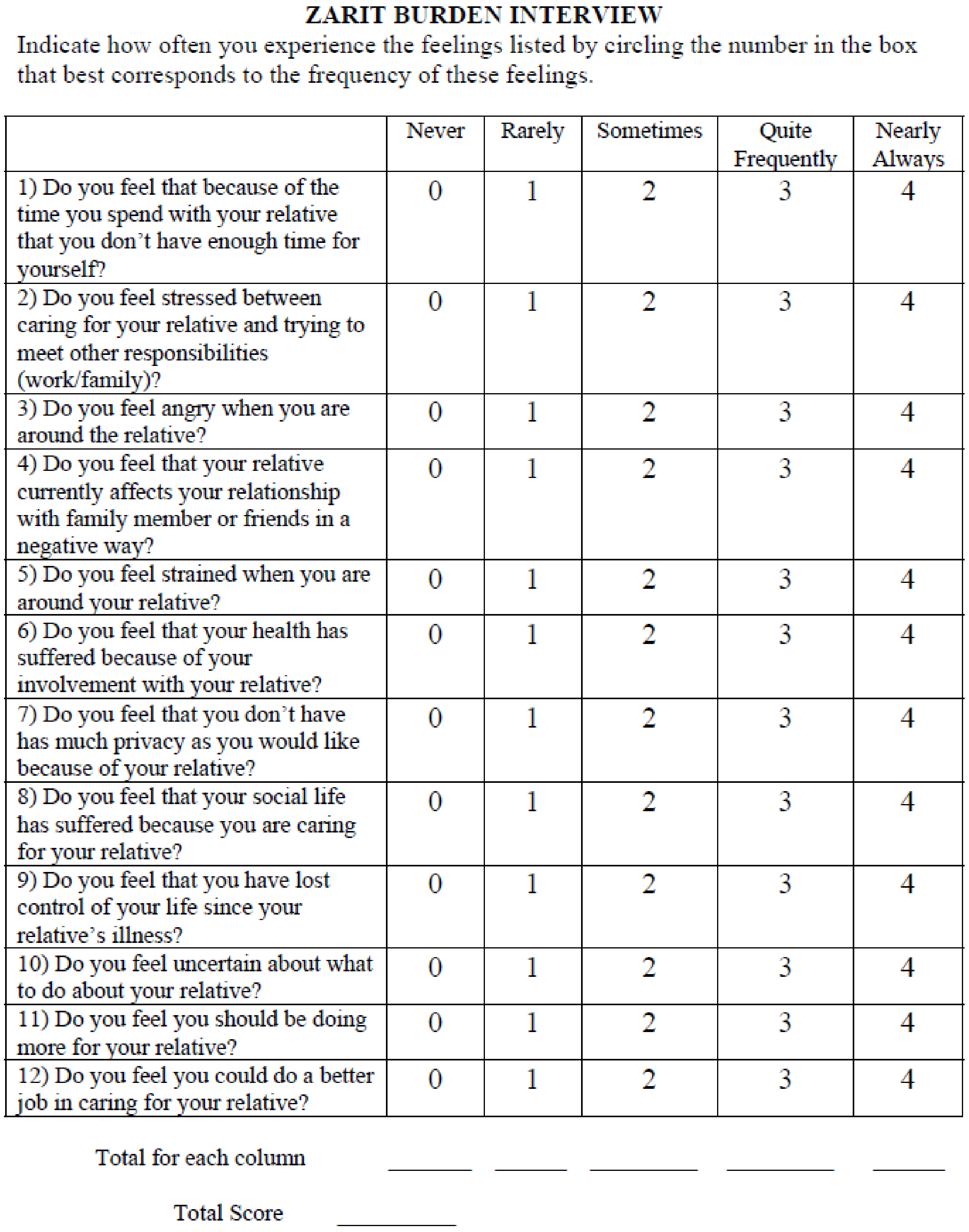
15. Can your patient move around without assistance? Yes (3) No (0)

Without assistance he is able to:	Always	Sometimes	Never
Visit his therapist	2	1	0
Go for a walk or shopping	2	1	0
Move around inside the whole house	2	1	0
Go to the lavatory	2	1	0
Get seated on the bed	2	1	0

16. Can your relative call for a physician by himself? Yes (3) No (0)

Always	2
Sometimes	1
Never	0

Assessment 7: Zarit Burden Interview (ZBI)



ZARIT BURDEN INTERVIEW

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your relative?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel that you don't have has much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Total for each column ________ ______ __________ __________ ______

Total Score ___________

Assessment 8: Non-standardized questions on global outcomes

1. Your overall change in feeling of quality of life by using the services
   3. It increases more than I thought it would
   2. It increases
   1. No change, no influence
   0. It decreases

2. Overall change in feeling of quality of life for your relative by using the services
   3. It increases more than I thought it would
   2. It increases
   1. No change, no influence
   0. It decreases

3. Overall support in independent living by using the services
   3. It increases more than I thought it would
   2. It increases
   1. No change, no influence
   0. It decreases

4. Your overall feeling of care responsibilities by using the services
   3. It decreases more than I thought it would
   2. It decreases
   1. No changes, no influence
   0. It increases

5. Your overall feeling of safety about the home environment
   3. I feel significantly safer
   2. I feel safer
   1. I do not feel safer
   0. I feel less safe

6. Your overall feeling of satisfaction about the system
   3. I am more satisfied than I thought I would be
   2. I am satisfied
   1. I am not satisfied
   0. I am disappointed

7. Would you want to use a system like this one after the study?
   3. I definitely would use a system like this
   2. I would consider using a system like this
   1. I would not consider using a system like this
   0. I would not use a system like this

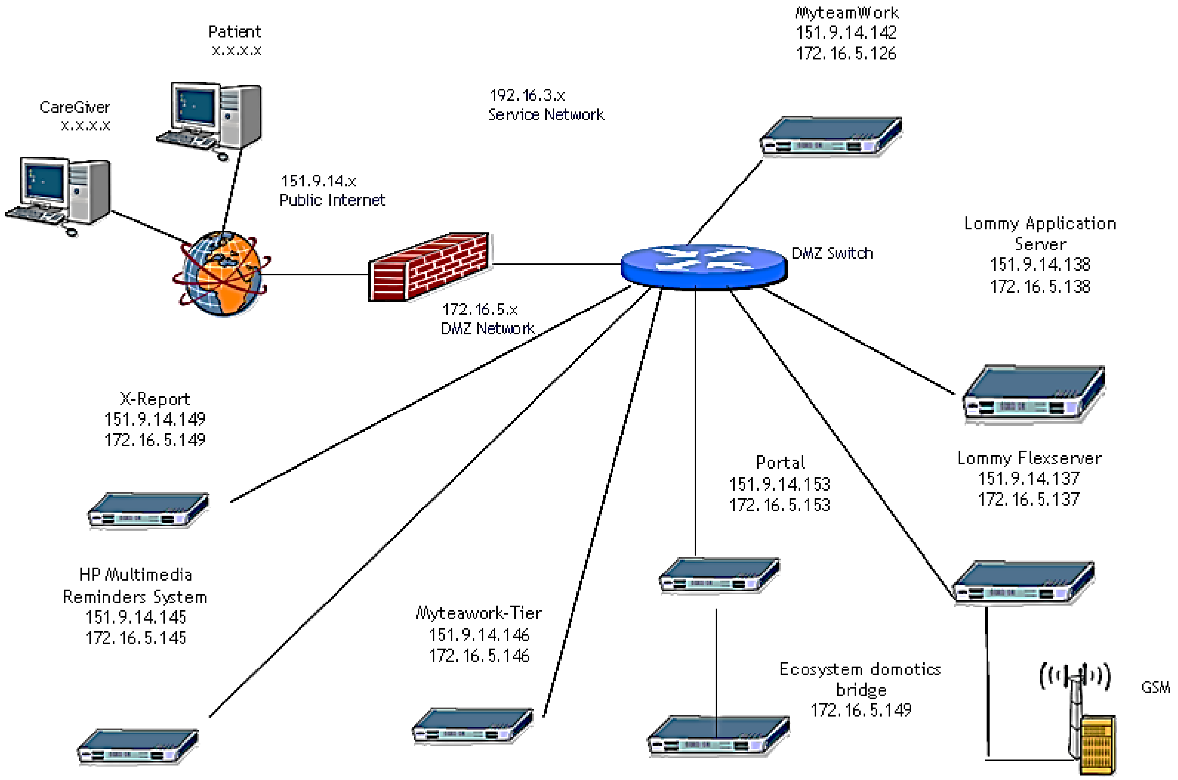
8. Would you be willing to pay for a service system like this?
   3. I would definitely pay for all of these services
   2. I would definitely pay for some of these services
   1. I would consider paying for some of these services
   0. I would not pay for these services at all

Appendix 6 ISISEMD system architecture

Table 32 Physical architecture components in ISISEMD [280]

Server name	Services controlled through the server
Portal	• Daily activities o the Carebox acts as the domotics controller and a communication device)
Ecosystem server	• Cooking monitor • Smoke detector • Water reminders • Refrigerator alarm • Sleeping sensor • Intelligent front door
HP Multimedia Reminder System	• Activity list • Reminders • Calendar
Lommy Flex Server	• Supports Lommy services
Lommy Application Server	• GPS/GSM/mobile telephony • Outdoor localization • Panic button • Fall alarm
X-Diagnostic (X-report server)	• Memory Lane • Remote care data
X-Diagnotic video communication (MCU and My Teamwork Server)	• Remote medical videoconferencing • Brain Games • Videophone

Figure 33 ISISEMD server physical architecture [280]



Appendix 7 Data from the participants

The following tables include the raw data that was analyzed from the participants in the ISISEMD study. The raw scores at baseline and final evaluation are given, including the range, mode, median, standard deviation, and mean. Additionally, gender, age, living arrangement of the person with dementia, and the caregiver's relationship to the person with dementia are given. The black boxes indicate where data is missing; B=Baseline score; and F=Final score.

Data set i: Belfast, North Ireland

Table 33 North Ireland intervention group, n=7

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation	Days Use
1	23	18	7	9	6	6	6	4	36,33	29,33	92	93	9	13	F	F	75	39	Alone	Child	324
2	27	21	23	14	6	6	4	4	44,67	35,33	88	93	20	21	F	F	75	62	Share	Spouse	238
3					6	2	4	0	44,00	33,67	33	27	20	18	M	M	75	50	Share	Child	198
4	19	16	9	9	6	6	3	2	36,67	32,00	69	97	31	34	F	F	72	41	Share	Child	137
5	15				3	3	3	0	30,67	23,00	63	56	29	28	F	M	69	69	Share	Spouse	102
6	29	30	26	29	6	5	3	4	33,33	37,67	85	108	23	31	M	F	70	69	Share	Spouse	86
7	29	19	23	20	6	6	4	4	45,33	43,33	93	107	15	15	M	M	83	82	Share	Spouse	37
Min	15,00	16,00	7,00	9,00	3,00	2,00	3,00	0,00	30,67	23,00	33,00	27,00	9,00	13,00	4 F	4 F	69,0	39,0	1 Alone	3 Child	37,0
Max	29,00	30,00	26,00	29,00	6,00	6,00	6,00	4,00	45,33	43,33	93,00	108,00	31,00	34,00	3 M	3 M	83,0	82,0	6 Share	4 Spouse	324,0
Mode	29,00	N/A	23,00	9,00	6,00	6,00	4,00	4,00	N/A	N/A	N/A	93,00	20,00	N/A			75,0	69,0			N/A
Median	25,00	19,00	23,00	14,00	6,00	6,00	4,00	4,00	36,67	33,67	85,00	93,00	20,00	21,00			75,0	62,0			137,0
SD	5,75	5,45	8,88	8,47	1,13	1,68	1,07	1,90	5,93	6,42	21,70	30,17	7,64	8,19			4,6	16,0			99,1
Mean	23,67	20,80	17,60	16,20	5,57	4,86	3,86	2,57	38,71	33,48	74,71	83,00	21,00	22,86			74,1	58,9			160,3

Table 34 North Ireland control group, n=9

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation
1	29	28	24	26	6	6	8	6	38,00	33,33	103	100	10	12	M	F	62	62	Share	Spouse
2	28	26	21	20	6	6	6	6	44,00	38,33	99	119	3	0	F	M	80	80	Share	Spouse
3	30	29	21	29	6	6	8	8	36,67	33,67	107	119	8	13	F	F	76	48	Alone	Child
4	30	27	18	20	6	6	4	3	32,67	33,67	101	102	17	18	M	F	82	79	Share	Spouse
5	25	23	18	18	6	6	5	4	39,33	41,67	94	95	0	2	F	M	80	80	Share	Spouse
6	19	19	[redacted]	[redacted]	3	4	0	1	29,00	30,00	77	77	12	12	M	F	87	79	Share	Spouse
7	22	25	17	15	6	6	6	7	27,67	31,33	113	88	2	10	F	F	67	37	Share	Child
8	29	29	23	24	6	6	4	4	34,67	35,33	103	103	1	3	M	F	85	82	Share	Spouse
9	29	27	18	[redacted]	6	6	8	7	44,67	36,00	113	110	14	18	F	M	77	38	Alone	Child
Min	19,00	19,00	17,00	15,00	3,00	4,00	0,00	1,00	27,67	30,00	77,00	77,00	0,00	0,00	5 F	6 F	62,0	37,0	2 Alone	3 Child
Max	30,00	29,00	24,00	29,00	6,00	6,00	8,00	8,00	44,67	41,67	113,00	119,00	17,00	18,00	4 M	3 M	87,0	82,0	7 Share	6 Spouse
Mode	29,00	29,00	18,00	20,00	6,00	6,00	8,00	6,00	N/A	33,67	103,00	119,00	N/A	12,00			80,0	80,0		
Median	29,00	27,00	19,50	20,00	6,00	6,00	6,00	6,00	36,67	33,67	103,00	102,00	8,00	12,00			80,0	79,0		
SD	3,93	3,22	2,62	4,86	1,00	0,67	2,60	2,26	5,97	3,56	10,96	13,76	6,21	6,69			8,2	19,2		
Mean	26,78	25,89	20,00	21,71	5,67	5,78	5,44	5,11	36,30	34,81	101,11	101,44	7,44	9,78			77,3	65,0		

Data set ii: Frederikshavn, Denmark

Table 35 Denmark intervention group, n=6

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation	Days use
3	22	27	19	20	5	6	2	3	34,67	34,33	106	105	4	4	M	F	66	67	Share	Spouse	256
4	[redacted]	[redacted]	[redacted]	[redacted]	6	6	8	7	35,83	39,33	104	130	5	0	M	F	81	[redacted]	Alone	Other	240
5	22	23	14	17	6	6	3	3	37,67	39,00	114	115	0	1	M	F	86	[redacted]	Alone	Other	245
6	25	27	20	16	6	6	4	4	32,67	36,33	116	107	6	23	F	M	82	59	Alone	Child	203
7	24	24	21	20	6	6	3	4	38,67	35,33	88	91	13	4	F	M	77	[redacted]	Share	Spouse	203
8	30	29	22	20	6	6	7	7	39,00	38,67	78	112	1	0	F	M	83	[redacted]	Alone	Other	143
Min	22,00	23,00	14,00	16,00	5,00	6,00	2,00	3,00	32,67	34,33	78,00	91,00	0,00	0,00	3 F	3 F	66,0	59,0	4 Alone	1 Child	143,0
Max	30,00	29,00	22,00	20,00	6,00	6,00	8,00	7,00	39,00	39,33	116,00	130,00	13,00	23,00	3 M	3 M	86,0	67,0	2 Share	2 Spouse	256,0
Mode	22,00	27,00	N/A	20,00	6,00	6,00	3,00	3,00	N/A	N/A	N/A	N/A	N/A	4,00			N/A	N/A		3 Other	203,0
Median	24,00	27,00	20,00	20,00	6,00	6,00	3,50	4,00	36,75	37,50	105,00	109,50	4,50	2,50			81,5	63,0			221,5
SD	3,29	2,45	3,11	1,95	0,41	0,00	2,43	1,86	2,48	2,12	15,01	12,84	4,62	8,85			7,1	5,7			41,7
Mean	24,60	26,00	19,20	18,60	5,83	6,00	4,50	4,67	36,42	37,17	101,00	110,00	4,83	5,33			79,2	63,0			215,0

Data set iii: Lappeenranta, Finland

Table 36 Finland intervention group, n=8

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation	Days use
1	21	19	19	13	6	6	6	4	34,67	35,00	105	78	14	9	F	F	65	64	Alone	Other	412
4	19	25	16	15	6	6	4	3	37,67	30,67	92	81	9	17	F	F	72	44	Alone	Child	267
5	24	21	18	18	6	5	6	3	41,00	36,00	84	91	17	24	F	F	83	57	Alone	Child	288
6	19	23	18	16	6	6	6	3	32,67	33,00	108	92	12	14	F	M	82	50	Alone	Child	274
7	29	29	18	23	5	4	3	3	28,33	25,67	74	68	20	22	F	M	82	81	Share	Spouse	290
8	23	21	19	15	6	6	8	7	36,67	31,67	110	99	9	13	F	F	73	46	Alone	Child	276
9	22	29	16	21	6	3	5	3	35,00	27,00	102	94	24	22	F	F	90	57	Alone	Child	269
10	23	20	17	14	5	6	3	3	25,00	23,33	74	94	15	10	F	F	73	57	Alone	Child	106
Min	19,00	19,00	16,00	13,00	5,00	3,00	3,00	3,00	25,00	23,33	74,00	68,00	9,00	9,00	8 F	6 F	65,0	44,0	7 Alone	6 Child	106,0
Max	29,00	29,00	19,00	23,00	6,00	6,00	8,00	7,00	41,00	36,00	110,00	99,00	24,00	24,00	0 M	2 M	90,0	81,0	1 Share	1 Spouse	412,0
Mode	19,00	21,00	18,00	15,00	6,00	6,00	6,00	3,00	N/A	N/A	74,00	94,00	9,00	22,00			82,0	57,0		1 Other	N/A
Median	22,50	22,00	18,00	15,50	6,00	6,00	5,50	3,00	34,83	31,17	97,00	91,50	14,50	15,50			77,5	57,0			275,0
SD	3,21	3,93	1,19	3,52	0,46	1,16	1,73	1,41	5,15	4,55	14,83	10,43	5,24	5,78			8,1	11,7			82,6
Mean	22,50	23,38	17,63	16,88	5,75	5,25	5,13	3,63	33,88	30,29	93,63	87,13	15,00	16,38			77,5	57,0			272,8

Table 37 Finland control group, n=8

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation
1	20	18	15	15	6	6	6	7	35,00	34,33	92	108	15	13	M	F	83	79	Share	Spouse
5	29	30	24	27	6	6	6	4	33,00	35,00	95	93	7	9	M	F	79	57	Alone	Child
6	23	28	18	18	6	6	6	3	26,67	24,00	74	107	13	20	F	F	87	57	Alone	Child
7	16	16	18	12	6	6	4	3	27,33	29,00	92	84	12	19	F	F	88	64	Alone	Child
8	26	24	21	21	6	6	2	2	26,00	33,00	72	82	6	20	M	F	84	84	Share	Spouse
9	24	27	22	20	6	6	4	4	30,33	32,67	97	107	14	13	M	F	91	64	Share	Spouse
10	18	16	13	11	6	5	2	2	25,00	22,33	73	82	11	11	F	M	82	55	Alone	Child
11	18	16	14	13	4	4	2	2	23,67	23,33	78	78	23	19	F	F	84	57	Alone	Child
Min	16,00	16,00	13,00	11,00	4,00	4,00	2,00	2,00	23,67	22,33	72,00	78,00	6,00	9,00	4 F	7 F	79,0	55,0	5 Alone	5 Child
Max	29,00	30,00	24,00	27,00	6,00	6,00	6,00	7,00	35,00	35,00	97,00	108,00	23,00	20,00	4 M	1 M	91,0	84,0	3 Share	3 Spouse
Mode	18,00	16,00	18,00	N/A	6,00	6,00	6,00	2,00	N/A	N/A	92,00	107,00	N/A	13,00			84,0	57,0		
Median	21,50	21,00	18,00	16,50	6,00	6,00	4,00	3,00	27,00	30,83	85,00	88,50	12,50	16,00			84,0	60,5		
SD	4,50	6,01	3,98	5,44	0,71	0,74	1,85	1,69	4,01	5,28	10,82	12,89	5,26	4,47			3,8	11,0		
Mean	21,75	21,88	18,13	17,13	5,75	5,63	4,00	3,38	28,38	29,21	84,13	92,63	12,63	15,50			84,8	64,6		

Data set iv: Trikala, Greece

Table 38 Greece intervention group, n=10

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation	Days use
1	23	22	13	13	5	5	6	7	36,00	33,67	97	102	12	5	F	M	75	30	Alone	Other	204
2	18	16	12	11	5	5	4	6	36,00	29,67	82	84	16	10	M	M	91	52	Alone	Child	233
3	15	14	11	11	4	4	1	2	26,33	30,67	73	78	21	10	F	F	82	57	Share	Child	219
4	20	19	16	16	5	3	5	1	24,00	31,33	85	99	13	10	F	M	86	55	Alone	Child	191
5	20	20	16	16	5	5	5	6	25,33	27,33	65	68	25	24	F	M	86	40	Share	Other	143
6	18	18	11	11	4	5	5	5	35,33	37,00	73	74	32	26	F	F	73	45	Share	Child	16
7	19	19	14	14	0	0	2	3	34,67	35,00	38	40	33	22	M	F	79	46	Share	Child	129
8	23	23	20	20	5	5	5	5	33,33	33,67	97	100	23	19	M	F	69	46	Share	Spouse	115
9	19	19	16	16	5	5	4	4	29,33	27,67	72	67	17	17	F	M	68	36	Share	Child	72
10	20	20	19	19	5	5	4	4	23,00	23,67	59	59	21	21	M	F	74	64	Share	Spouse	50
Min	15,00	14,00	11,00	11,00	0,00	0,00	1,00	1,00	23,00	23,67	38,00	40,00	12,00	5,00	6 F	5 F	68,0	30,0	3 Alone	5 Child	16,0
Max	23,00	23,00	20,00	20,00	5,00	5,00	6,00	7,00	36,00	37,00	97,00	102,00	33,00	26,00	4 M	5 M	91,0	64,0	7 Share	2 Spouse	233,0
Mode	20,00	19,00	16,00	11,00	5,00	5,00	5,00	6,00	36,00	33,67	97,00	N/A	21,00	10,00			86,0	46,0		3 Other	N/A
Median	19,50	19,00	15,00	15,00	5,00	5,00	4,50	4,50	31,33	31,00	73,00	76,00	21,00	18,00			77,0	46,0			136,0
SD	2,37	2,62	3,16	3,27	1,57	1,62	1,52	1,89	5,30	4,04	17,80	19,92	7,23	7,17			7,8	10,2			74,8
Mean	19,50	19,00	14,80	14,70	4,30	4,20	4,10	4,30	30,33	30,97	74,10	77,10	21,30	16,40			78,3	47,1			137,2

Table 39 Greece control group, n=5

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation
1	16	14	12	11	6	6	7	6	37,67	33,00	88	86	10	13	F	F	80	52	Share	Child
2	17	16	13	12	6	6	7	6	41,00	33,00	88	86	10	14	F	F	76	52	Share	Child
3	19	18	14	14	5	5	6	5	35,00	31,33	72	72	33	35	F	F	69	57	Share	Spouse
4	19	16	16	14	5	4	5	5	42,33	38,67	80	84	34	34	M	F	81	65	Share	Spouse
5	19	19	16	16	4	3	3	3	31,33	31,33	85	85	19	20	F	M	94	63	Share	Child
Min	1,00	14,00	12,00	11,00	4,00	3,00	3,00	3,00	31,33	31,33	72,00	72,00	10,00	13,00	4 F	4 F	69,0	52,0	0 Alone	3 Child
Max	5,00	19,00	16,00	16,00	6,00	6,00	7,00	6,00	42,33	38,67	88,00	86,00	34,00	35,00	1 M	1 M	94,0	65,0	5 Share	2 Spouse
Mode	N/A	16,00	16,00	14,00	6,00	6,00	7,00	6,00	N/A	33,00	88,00	86,00	10,00	N/A			N/A	52,0		
Median	3,00	16,00	14,00	14,00	5,00	5,00	6,00	5,00	37,67	33,00	85,00	85,00	19,00	20,00			80,0	57,0		
SD	1,58	1,95	1,79	1,95	0,84	1,30	1,67	1,22	4,47	3,02	6,77	5,98	11,82	10,66			9,1	6,1		
Mean	3,00	16,60	14,20	13,40	5,20	4,80	5,60	5,00	37,47	33,47	82,60	82,60	21,20	23,20			80,0	57,8		

Data set v: All Intervention data

Table 40 Intervention group data, n=31

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation	Days use
Sum	640	611	473	456	163	154	136	118	1063,8	1009,3	2619	2709	509	487	21 Female	18 Female	2397	1465	15 Alone	9 Spouse	5966
Diff		-29		-17		-9		-18		-54,5		90		-22	10 Males	13 Male			16 Share	15 Child	
Min	15	14	7	9	0	0	1	0	23	23	33	27	0	0			65	30		7 Other	16
Max	30	30	26	29	6	6	8	7	45,33	43,33	116	130	33	34			91	82			412
Mode	23	19	16	20	6	6	4	4	34,67	33,67	92	93	9	10			75	57			203
Median	22	21	17,5	16	6	5	4	4	35,00	33,67	85	93	16	17			75	55			203
SD	3,99	4,32	4,43	4,47	1,24	1,45	1,69	1,85	5,78	5,04	20,33	22,27	8,80	9,13			7,0	12,9			92,8
Mean	22,07	21,82	16,89	16,29	5,26	4,97	4,39	3,81	34,32	32,56	84,48	87,39	16,42	15,71			77,3	54,3			192,5
Diff		-0,25		-0,61		-0,29		-0,58		-1,76		2,90		-0,71							

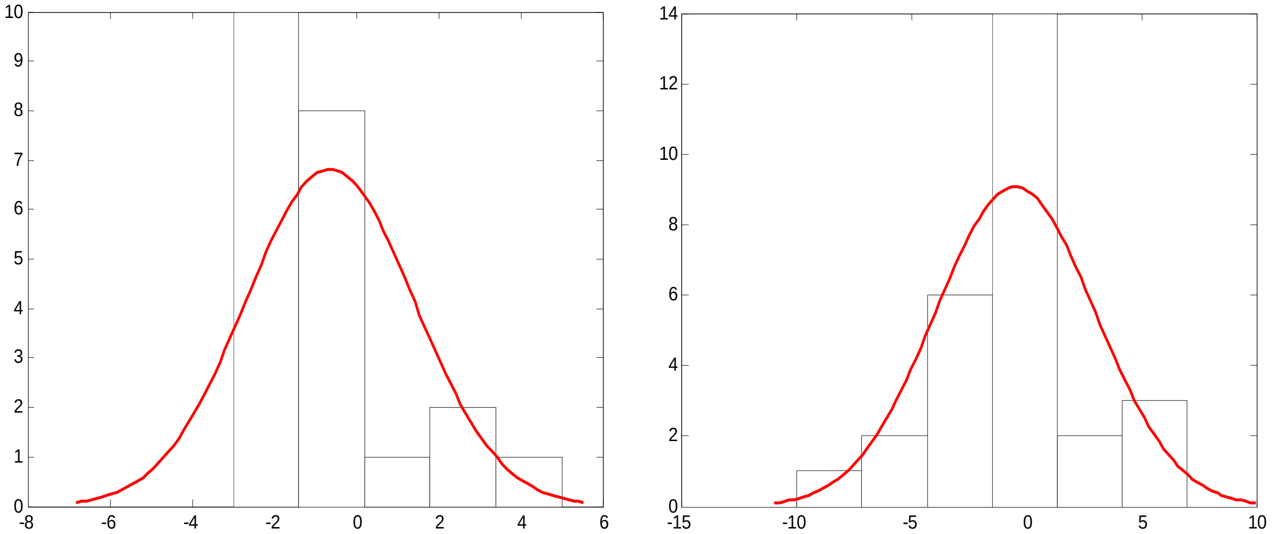
Data set vi: All Control data

Table 41 Control group data, n=22

Dyad	B MMSE	F MMSE	B MoCA	F MoCA	B ADL	F ADL	B IADL	F IADL	B QOL	F QOL	B SQLC	F SQLC	B ZBI	F ZBI	EP Sex	ICG Sex	EP Age	ICG Age	Living Status	Relation
Sum	505	491	376	356	123	121	109	98	741	714,33	1996	2067	274	328	13 Female	17 Female	1774	1391	7 Alone	11 Spouse
Diff		-14		-20		-2		-11		-26,67		71		54	9 Male	5 Male			15 Share	11 Child
Min	16	14	12	11	3	3	0	1	23,67	22,33	72	72	0	0			62	37		
Max	30	30	24	29	6	6	8	8	44,67	41,67	113	119	34	35			94	84		
Mode	29	16	18	20	6	6	6	6	35	31,33	103	119	10	13			80	57		
Median	22,50	23,50	18	17	6	6	5,50	4	33,83	33	92	90,50	11,50	13			81,5	62,5		
SD	5,07	5,48	3,71	5,48	0,85	0,91	2,19	1,97	6,31	4,74	13,12	13,78	8,92	8,55			7,6	14		
Mean	22,95	22,32	17,90	17,80	5,59	5,50	4,95	4,45	33,68	32,47	90,73	93,95	12,45	14,91			80,6	63,2		
Diff		-0,64		-0,10		-0,09		-0,50		-1,21		3,23		2,45						

Data set vii: Distribution fit of assessment outcomes

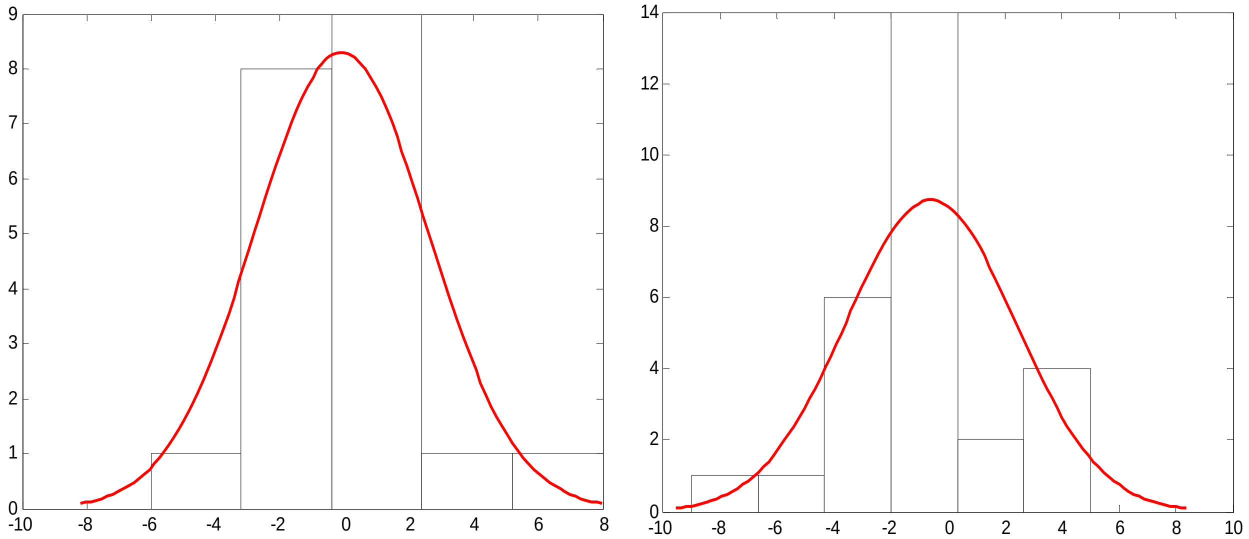
Figure 34 Control MSME and Intervention MMSE



Control mean change -0,64
95% CI [-1,55 to 0,28]
p=0,16

Intervention mean change -0,50
95% CI [-1,85 to 0,85]
p=0,46

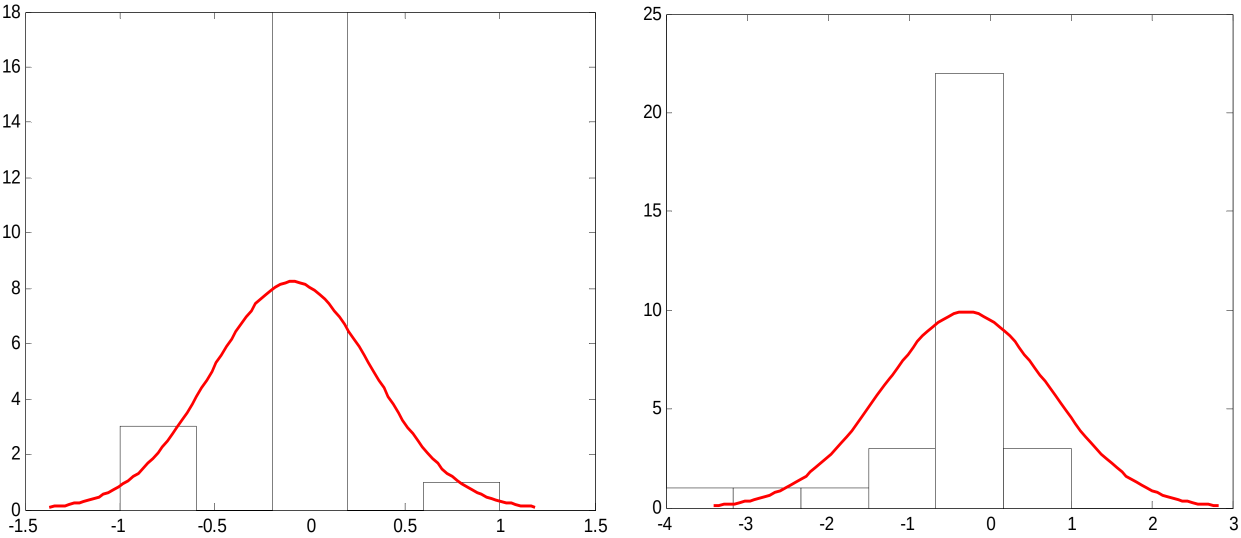
Figure 35 Control MoCA and Intervention MoCA



Control mean change -0,10
95% CI [-1,36 to 1,16]
p=0,87

Intervention -0,61
95% CI [-1,76 to 0,55]
p=0,29

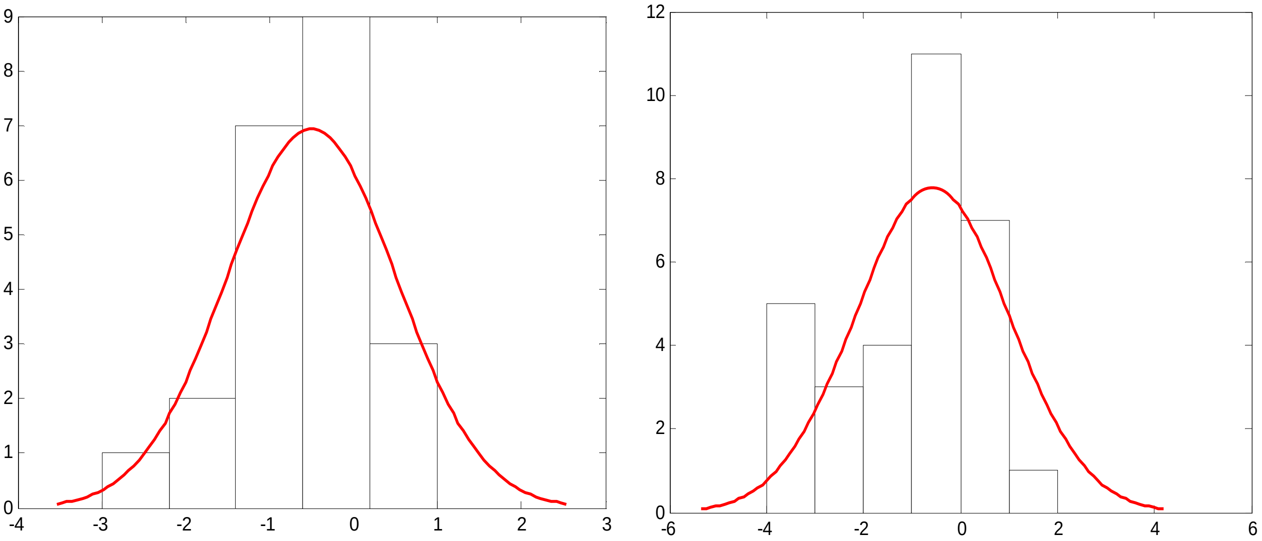
Figure 36 Control and Intervention ADL



Control mean change -0,09
95% CI [-0,28 to 0,10]
p=0,33

Intervention mean change -0,29
95% CI [-0,67 to 0,09]
p=0,13

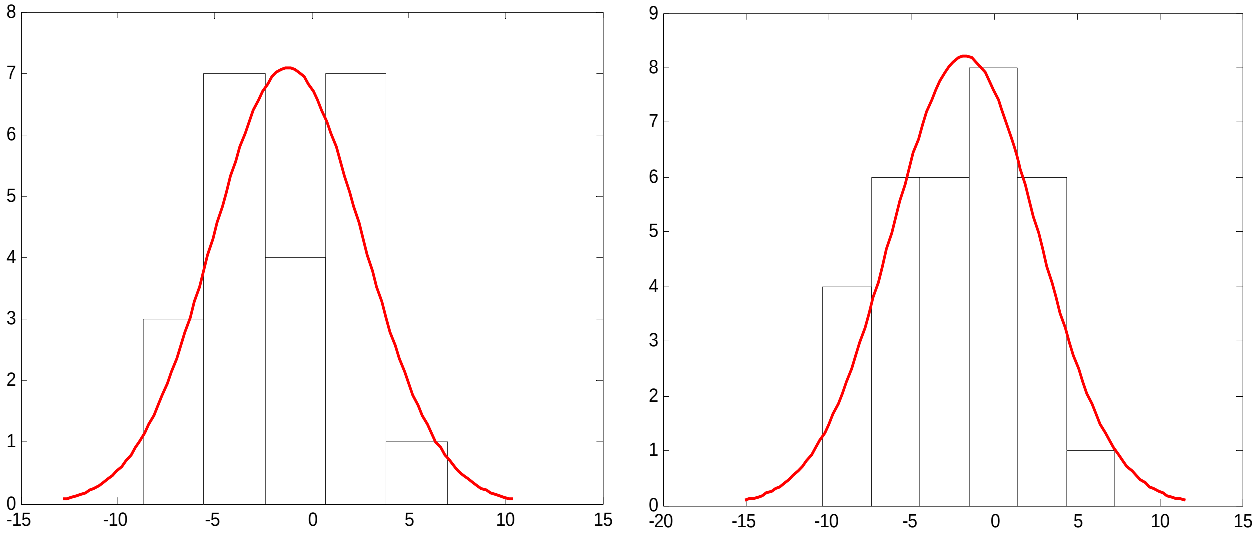
Figure 37 Control and Intervention IADL



Control mean change -0,50
95% CI [-0,95 to -0,05]
p=0,03*

Intervention mean change -0,58
95% CI [-1,16 to 0,001]
p=0,05*

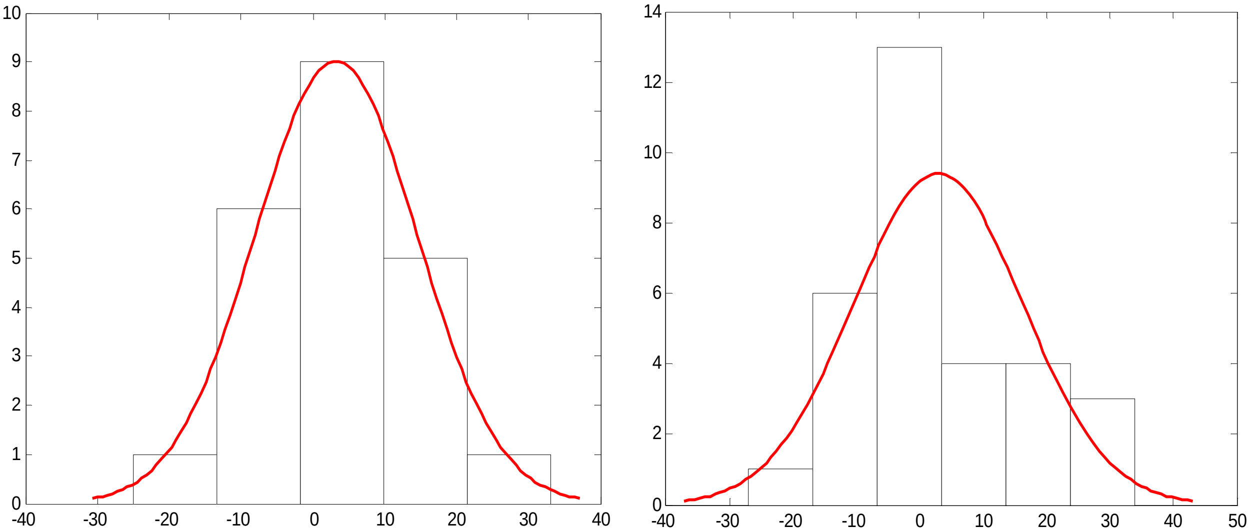
Figure 38 Control and Intervention QOL-AD



Control mean change -1,21
95% CI [-2,93 to 0,51]
p=0,16

Intervention mean change -1,76
95% CI [-3,39 to -0,13]
p=0,04*

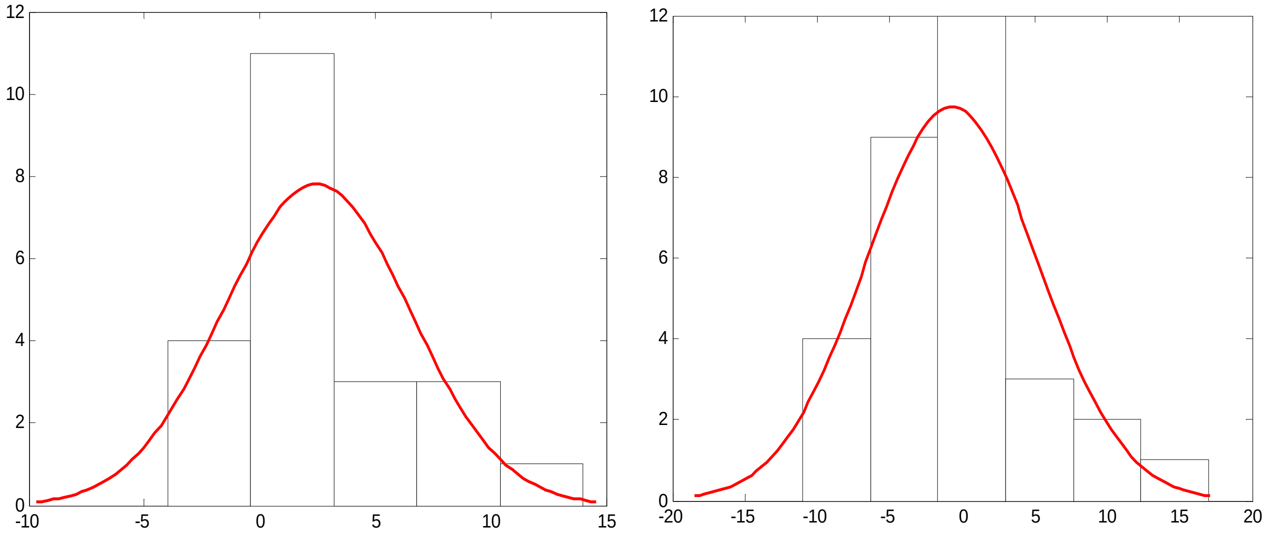
Figure 39 Control and Intervention SQLC



Control mean change 3,23
95% CI [-1,78 to 8,23]
p=0,19

Intervention mean change 2,90
95% CI [-2,00 to 7,80]
p=0,24

Figure 40 Control and intervention ZBI



Control mean change 2,45
95% CI [0,66 to 4,25]
p=0,01**

Intervention mean change -0,71
95% CI [-2,89 to 1,47]
p=0,51

Data set viii: Pearson's correlations

Results are given in p-value significance. Green highlighted boxes indicate significant correlations.

Table 42 Control group Pearson's correlations, n=22

	MMSE	MoCA	ADL	IADL	QOL-AD	SQLC	ZBI	EP AGE	ICG AGE
MMSE									
MoCA	0,72								
ADL	0,26	0,37							
IADL	0,30	0,53	0,72						
QOL-AD	0,24	0,69	0,06	0,19					
SQLC	0,72	0,33	0,86	0,35	0,48				
ZBI	0,21	0,97	0,93	0,33	0,16	0,53			
EP AGE	0,53	0,21	0,93	0,42	0,12	0,07	0,53		
ICG AGE	0,21	0,90	0,05*	0,37	0,05*	0,11	0,42	0,06	

Table 43 Intervention group Pearson's correlations, n=31

	MMSE	MoCA	ADL	IADL	QOL-AD	SQLC	ZBI	LENGTH	SHORT	LONG	EP AGE	ICG AGE
MMSE												
MoCA	0,01**											
ADL	0,21	0,02**										
IADL	0,83	0,87	0,001**									
QOL-AD	0,45	0,52	0,14	0,18								
SQLC	0,03*	0,56	0,59	0,21	0,18							
ZBI	0,49	0,87	0,67	0,22	0,59	0,59						
LENGTH	0,31	0,71	0,31	0,10	0,19	0,01**	0,49					
SHORT	0,42	0,84	0,008**	0,04*	0,66	0,63	0,79					
LONG	0,56	0,80	0,65	0,007**	0,57	0,02**	0,73					
EP AGE	0,98	0,19	0,08	0,96	0,59	0,36	0,80	0,49	0,21	0,11		
ICG AGE	0,42	0,92	0,67	0,92	0,67	0,96	0,40	0,99	0,27	0,41	0,71	

Data set ix: Subgroup analysis

Table 44 Subgroup analysis outcomes

Subgrouping	Control Subgroup	Intervention Subgroup	Significant differences between groups	Significant differences within groups
Effects in caregiver burden	Positive effects		Highly significant difference in ZBI and IADL outcomes	Non-significant improvement in ZBI, highly significant decline in MoCA, and significant improvement in SQLC.
	Negative effects			Significant decline in IADL.
		Positive effects	Highly significant difference in ZBI outcomes and length of use.	Highly significant improvement in ZBI.
		Negative effects		Highly significant decline in ZBI and IADL.
Age	Younger participants with dementia		Highly significant differences in the age of the person with dementia, the caregiver ages, and in QOL-AD outcomes.	Highly significant decrease in IADL and QOL-AD, and a highly significant increase in ZBI.
	Older participants with dementia			No significant differences from baseline.
	Younger caregivers		Highly significant differences in the age of the person with dementia and in caregiver age, and a significant difference in QOL-AD outcomes.	Highly significant decline in IADL, significant decline in QOL-AD, and highly significant increase in ZBI.
	Older caregivers			No significant differences from baseline.
		Younger participants with dementia	Highly significant differences in age of the person with dementia.	Highly significant decline in QOL-AD.
		Older participants with dementia		No significant differences from baseline.
		Younger caregivers	Highly significant difference in caregiver age.	Significant decline in QOL-AD.
		Older caregivers		No significant differences from baseline.

Subgrouping	Control Subgroup	Intervention Subgroup	Significant differences between groups	Significant differences within groups
Living arrangement	Alone		Significant differences in caregiver ages (alone group is an average of 13,95 years younger).	No significant differences from baseline.
	Cohabitating			No significant differences from baseline.
		Alone	Highly significant difference in length of use (alone group used an average of 101,8 days longer).	Highly significant decline in IADL.
		Cohabitating		No significant differences from baseline.
Caregiver relationship	Spouses		Highly significant difference in caregiver age (spouses are an average of 21 years older).	Significant decline in MMSE and significant increase in SQLC.
	Adult children			Significant decline in IADL and a highly significant increase in ZBI
		Spouses	Spouses are highly significantly older than adult children (by an average of 17,8 years) and other caregivers (by an average of 22,8 years).	No significant differences from baseline.
		Adult children		Significant decline in IADL.
		Other		Highly significant improvement in ZBI.

Appendix 8 Overview of significant results

Table 45 Analysis of the data, significant results, and hypothesis testing

Research question	Test	Group	Results	Hypothesis	Interpretation
Are there significant changes within the intervention group?	Paired t-tests on baseline to final scores	Intervention	IADL declined p=0,05*. QOL-AD declined p=0,04*.		Yes, there are significant declines in independent functioning and QOL of the person with dementia.
Are there significant changes within the control group?	Paired t-tests on baseline to final scores	Control	IADL declined p=0,03*. ZBI increased (declined) p=0,01**.		Yes, there is significant decline in independent functioning and significant increase in caregiver burden.
Are there significant differences between the intervention and control group outcomes?	Independent t-tests for score changes from baseline to final	Between Intervention and Control	Highly significant difference in ZBI p=0,03**.	Intervention group will show improvement or less decline in than the control group	Hypothesis is supported
Will using gerontechnology have positive effects on physical functioning?	ADL	Between Intervention and Control	The two groups do not show significant differences in ADL (p=0,40) .	Intervention group will show improvement or less decline in ADL than the control group	Null hypothesis cannot be rejected
Will using gerontechnology have positive effects on independent functioning?	IADL	Between Intervention and Control	The two groups do not show significant differences in IADL (p=0,83) outcomes.	Intervention group will show improvement or less decline in IADL than the control group	Null hypothesis cannot be rejected
Will using gerontechnology have positive effects on independent living?	Non-standardized questionnaire on feeling of change in independent living for the person with dementia	Intervention	61,3% reported increased independent living. 37,1% report maintained independence .	Intervention group will report an increase in independent living	Gerontechnology has positive effects on independent living. Hypothesis is supported
Will using gerontechnology have positive effects on QOL in the person with dementia?	QOL-AD	Between Intervention and Control	Non-significant difference between the two groups, p=0,64.	Intervention group will show improvement or less decline in QOL-AD than the control group	No, there is not a significant difference between the two groups in QOL outcomes of the person with dementia Null hypothesis cannot be rejected
	Non-standardized questionnaire on feeling of change in person with dementia's QOL	Intervention	The intervention group shows an increased QOL for 62,9% of participants with dementia and maintained QOL for the remaining 37,1%.	ICT services will increase QOL for 50% of participants with dementia	Yes, gerontechnology has positive effects on QOL in the majority of the participants with dementia. Hypothesis is supported

Research question	Test	Group	Results	Hypothesis	Interpretation
Will using gerontechnology have positive effects on QOL in the caregivers?	SQLC	Between Intervention and Control	Non-significant difference between the two groups, p=0,93.	Intervention group will show improvement or less decline in SQLC than the control group	No, there is not a strong difference between the two, they experienced similar increases in QOL. Null hypothesis cannot be rejected
	Non-standardized questionnaire on feeling of change in caregiver QOL	Intervention	The intervention group shows an increase in QOL for 70,9% of caregivers and maintained QOL for the remaining 19,4%.	ICT services will increase QOL for 70% of caregivers	Yes, gerontechnology has positive effects on QOL in all of the caregivers. Hypothesis is supported
Will using gerontechnology have positive effects on caregiver burden?	Independent t-tests on ZBI outcomes	Between Intervention and Control	Significant difference is ZBI p=0,03* (intervention group improved, control declined).	Intervention group will show improvement or less decline in ZBI than the control group	Hypothesis is supported
	Non-standardized questionnaire on feeling of change in care responsibilities	Intervention	100% of caregivers reported positive effects on care responsibilities. • 61,3% reported decreased responsibilities • 35,5% reported maintained responsibilities	ICT services will reduce burden in 60% of the caregivers	Yes, gerontechnology has reduced burden in all of the caregivers. Hypothesis is supported
Is there a linear relationship between independent functioning and caregiver burden?	Pearson's correlation between IADL and ZBI score changes	Intervention	Non-significant, negative relationship p=0,22.		No, There is no evidence of a strong correlation.
	Pearson's correlation between IADL and ZBI score changes	Control	Non-significant, negative relationship p=0,32.		No, There is no evidence of a strong correlation.
Will using gerontechnology have positive effects on physical and/or independent functioning?	Pearson's correlation between ADL and IADL change	Intervention	Strong, positive relationship in decline, p=0,001**.		No, the intervention group did not show improvement or less decline than the control group.
	Pearson's correlation between ADL and IADL change	Control	Non-significant, negative relationship in decline p=0,99.		
Does independent functioning influence QOL in the person with dementia?	Pearson's correlation between IADL and QOL-AD	Intervention	Non-significant positive relationship in decline p=0,18.		No, there is not a strong linear relationship between independent functioning and QOL of the person with dementia.

Research question	Test	Group	Results	Hypothesis	Interpretation
	Pearson's correlation between IADL and QOL-AD	Control	Non-significant, positive relationship in decline p=0,19.		No, there is not a linear relationship between independent functioning and QOL of the person with dementia.
	Pearson's correlation between QOL-AD and IADL	Intervention dichotomized by positive and negative QOL-AD outcomes	Those with positive QOL-AD outcomes had non-significant negative relationship (p=0,45). Those with negative QOL-AD outcomes had positive relationship in decline (p=0,01**).		No, improvement in QOL-AD was not influenced by IADL. Yes, declines in IADL are highly correlated with declines in QOL-AD.
	Pearson's correlation between QOL-AD and IADL	Control dichotomized by positive and negative QOL-AD outcomes	Non-significant, positive relationships (positive effects in QOL-AD p=0,72; negative effects in QOL-AD p=0,31.		No, there is no evidence of strong correlations.
Are there significant differences in outcomes within the intervention group dichotomized by ZBI?	Independent t-tests of the difference in score changes between groups	Intervention, dichotomized by positive/negative effects in ZBI	No significant difference in assessment scores (other than ZBI); length of use p=0,04*.		No, there are no significant differences in those who have positive and those who have negative effects in ZBI.
Are there significant differences in outcomes within the control group dichotomized by ZBI?	Independent t-tests of the difference in score changes between groups	Control, dichotomized by positive/negative effects in ZBI	Only significant difference aside from ZBI was in IADL p=0,01**, the group who had positive effects in ZBI had an increase in IADL and those who had negative effects in ZBI had decreases in IADL.		Yes, positive effects in ZBI were associated with positive effects in IADL, and negative effects in ZBI were associated with negative effects in IADL.
Are there significant differences in IADL outcomes within the intervention group dichotomized by ZBI?	Paired t-tests on IADL changes from baseline to final in both groups	Intervention (incl DK), dichotomized by positive/negative effects in ZBI	In the positive effect group, IADL p=0,31. In the negative effect group, IADL p=0,04*.		Yes, those with negative effects in ZBI have highly significant declines in IADL.
Are there significant differences in IADL outcomes within the control group dichotomized by ZBI outcomes?	Paired t-tests on IADL changes from baseline to final in both groups	Control, dichotomized by positive/negative effects in ZBI	IADL decline p=0,004** for the group who had increases in ZBI (negative effects), and non-significant improvement in IADL (p=0,17) in the subgroup with positive effects in ZBI.		Yes, those with negative effects in ZBI have highly significant declines in IADL.

Research question	Test	Group	Results	Hypothesis	Interpretation
Are there linear relationships in assessment outcomes within the intervention group when dichotomized by length of use?	Pearson's correlation in outcomes by length of use	Intervention (incl DK), dichotomized by length of use	The short use group has a highly significant positive relationship in ADL and IADL declines (p=0,01**) and in MMSE and MoCA declines (p=0,01**), and significant negative relationships between length of use and ADL (p=0,01**) and IADL (p=0,04*). The long use group has highly significant negative correlations between length of use and IADL (p=0,01**) and SQLC (p=0,02**).		Yes, there are significant linear relationships found when dichotomized by length of use.
Are there significant differences between the intervention group who had longer and shorter use of the intervention?	Independent t-tests on differences between long and short use groups	Intervention, dichotomized by length of use	Only significant difference was in SQLC p=0,02**, short group improved and long group declined.		Yes, there is a highly significant difference in caregiver QOL, where the short use group improved and the long use group declined.
Will participants be satisfied with the gerontechnology services?	Non-standardized questionnaire on user satisfaction	Intervention	88,7% of participants are satisfied with the intervention services.	75% of intervention participants will report satisfaction with the services	Yes, more than ¾ of the participants are satisfied with the intervention.
Will using gerontechnology have positive effects on a feeling of safety?	Non-standardized questionnaire on feeling of safety	Intervention	The intervention group shows an increase in feeling of safety in 80,6% of participants and maintained feeling of safety in the remaining 19,4%.	Intervention participants will report an increase in feeling of safety in 30% of the participants	Yes, participants, especially the caregivers, feel safer with the gerontechnology.
Would people want to use services like these?	Non-standardized questionnaire on acceptance	Intervention	90,3% of participants would consider or definitely want to use an intervention like this.	75% of intervention caregivers will report a desire to continue using services	Yes, more than ¾ of participants would want to use services like this.
Will end users be willing to pay for gerontechnology services?	Non-standardized questionnaire on user willingness to pay	Intervention	53,2% of participants are willing to pay for these services 58,1% of the adults with dementia and 48,48% of the caregivers (12,9% did not answer).	Participants will report willingness to pay for telecare services.	Yes, the majority of participants are willing to pay for telecare services like these.
Overall difference	ADL, IADL, QOL-AD, SQLC, and ZBI	Compared mean changes between the groups	The two types of care do not show significant differences in outcomes (p=0,48).	Intervention group participants will have significantly different (better) outcomes.	The null hypothesis cannot be rejected.